Families of young children with autism spectrum disorder in Sweden: The role of culture and intergenerational support

Rano Zakirova Engstrand
Families of young children with autism spectrum disorder in Sweden: The role of culture and intergenerational support

Rano Zakirova Engstrand

Academic dissertation for the Degree of Doctor of Philosophy in Special Education at Stockholm University to be publicly defended on Monday 28 October 2019 at 10.00 in David Magnussonsalen (U31), Frescati Hagväg 8.

Abstract

Children with autism spectrum disorder (ASD) have shown high variability in learning outcomes in response to evidence-based interventions, suggesting a need for individualization of intervention programmes for each child and his/her family. To explain this variability and develop effective intervention strategies research suggested focusing on identification of important contextual factors that might influence the effectiveness of a specific intervention for each child such as family cultural characteristics and characteristics of service settings and systems. The overarching aim of the thesis was to identify and describe proximal and distal environmental factors and processes affecting implementation and provision of interventions and services for young children with ASD and their families within the context of the Swedish support system. Two theoretical models guided the research project: Bronfenbrenner’s bioecological model of human development and Wachs’s multiple-influences model of individual variability. The specific objectives addressed using a mixture of qualitative and quantitative methods were: (i) to investigate the scope of reporting ethnicity and other cultural factors in research publications by Swedish scholars involved in empirical research in ASD in children and youth (Study 1); (ii) to explore perceptions of autism, beliefs about its causes, and treatment preferences expressed by parents of children with ASD from culturally, ethnically and linguistically diverse backgrounds (Study 2), and (iii) to explore grandparents’ perceived needs in relation to having a young grandchild with ASD (Study 3).

The results of data triangulation across the three studies showed that within the context of the Swedish support system, three proximal environmental factors were associated with identification of ASD in young children and families’ use of services and interventions before and after the child was diagnosed with ASD. These were parents’ belief systems (including perceptions about child’s autism, help-seeking behaviours, and treatment preferences); the role of preschool teachers, and the role of other service providers, such as healthcare professionals. Data triangulation singled out seven groups of distal environmental factors: beliefs of extended family; family cultural, ethnic and linguistic background; family socio-economic characteristics (occupation and education level); Swedish formal support system enacted through various legislative acts; international laws and regulations; information sources (mass media and social media), and conceptualization and clinical definition of ASD (as reflected in DSM and ICD classifications). Findings also highlight the importance of taking into consideration of role of ASD researchers as an additional distal environmental factor affecting implementation of interventions and services for culturally and linguistically diverse children with ASD and their families.

The results of the studies provide insights into understanding of families’ belief systems about ASD causes, treatment preferences, and needs that are essential for planning and provision of family-level early interventions for children with ASD in the cultural context of Sweden. Implications for practice and future research are discussed.

Keywords: young children with autism, system-theory perspective, culturally diverse families, parents’ explanatory models of autism, grandparents’ needs, cultural formulation, Swedish support system.

Stockholm 2019
http://urn.kb.se/resolve?urn=urn:nbn:se:su:diva-172822

ISBN 978-91-7797-819-0

Department of Special Education

Stockholm University, 106 91 Stockholm
FAMILIES OF YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER IN SWEDEN: THE ROLE OF CULTURE AND INTERGENERATIONAL SUPPORT

Rano Zakirova Engstrand
Families of young children with autism spectrum disorder in Sweden: The role of culture and intergenerational support

Rano Zakirova Engstrand
To My Family
List of Papers


Contents

Abbreviations .................................................................................................................. 1
Definitions .......................................................................................................................... 2
Introduction ......................................................................................................................... 3
Aim and Objectives ............................................................................................................. 5
System Theories as Theoretical Framework ..................................................................... 6
  Biocological model of human development ................................................................ 7
  The multiple-influences model ...................................................................................... 8
  Explanatory Models of Illness or Disability ................................................................. 11
Understanding Autism in Children .................................................................................. 12
  Historical and current conceptualizations and description of autism ....................... 12
  Standardized diagnostic tools for ASD ...................................................................... 15
  The Importance of Family ............................................................................................ 17
  Culture ............................................................................................................................ 19
  Treatment and Intervention Approaches .................................................................... 22
  Clinical definitions of autism in DSM and ICD over time ......................................... 29
  Controversies with diagnostic classifications for mental disorders ......................... 34
  ASD in the cultural context of Sweden ....................................................................... 41
Methods ............................................................................................................................ 44
  Mixed Methods Design ................................................................................................. 44
    Philosophical Framework ......................................................................................... 44
    Rationale for using mixed methods design ............................................................... 45
    The role of the researcher ......................................................................................... 46
Sample/Participants .......................................................................................................... 47
  Study 1 .......................................................................................................................... 47
  Study 2 .......................................................................................................................... 47
  Study 3 .......................................................................................................................... 48
Instrumentation .................................................................................................................. 49
  Demographic survey .................................................................................................... 49
  Semi-structured in-depth interview .............................................................................. 50
  Family demographic profile (FDP) ............................................................................ 50
  GAP-REACH checklist ............................................................................................... 50
  Explanatory model (Supplementary module 1) ........................................................ 51
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>APA</td>
<td>American Psychiatric Association</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>CAM</td>
<td>Complementary and Alternative Medicine</td>
</tr>
<tr>
<td>CAPC</td>
<td>Child and Adolescent Psychiatry Clinic</td>
</tr>
<tr>
<td>CFI</td>
<td>Cultural Formulation Interview</td>
</tr>
<tr>
<td>CHC</td>
<td>Child Habilitation Center</td>
</tr>
<tr>
<td>CHCC</td>
<td>Child Health Care Center (i.e. BVC, in Swedish)</td>
</tr>
<tr>
<td>CTM</td>
<td>Comprehensive Treatment Models</td>
</tr>
<tr>
<td>DSM</td>
<td>Diagnostic and Statistical Manual of Mental Disorders</td>
</tr>
<tr>
<td>EBP</td>
<td>Evidence-based Practices</td>
</tr>
<tr>
<td>EFI</td>
<td>Ecocultural Family Interview</td>
</tr>
<tr>
<td>EM</td>
<td>Explanatory Models</td>
</tr>
<tr>
<td>FDP</td>
<td>Family Demographic Profile</td>
</tr>
<tr>
<td>GAP-R</td>
<td>Checklist of the Cultural Committee of the Group for the Advancement of Psychiatry (GAP) on Race, Ethnicity, And Culture in Health (REACH)</td>
</tr>
<tr>
<td>IAAC</td>
<td>Interagency Autism Coordinating Committee</td>
</tr>
<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>NAC</td>
<td>National Autism Center</td>
</tr>
<tr>
<td>NPDC</td>
<td>National Professional Development Center on ASD</td>
</tr>
<tr>
<td>NSP</td>
<td>National Standards Project</td>
</tr>
<tr>
<td>RDoC</td>
<td>Research Domain Criteria</td>
</tr>
<tr>
<td>SDQ-Swe</td>
<td>Strength and Difficulties Questionnaire – Swedish version</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNCRPD</td>
<td>UN Convention of the Rights of Persons with Disability</td>
</tr>
<tr>
<td>WHA</td>
<td>World Health Assembly</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Definitions

Distal environmental factors
Refers to “cultural and subcultural characteristics, societal institutions, societal disruptions, place of residence, social class, and parental work situation or social support system” (Wachs, 2000, p. 153).

Early intervention/early childhood special education
Denotes a system of practices “for infants and young children with identified disabilities or at clear risk of disability, and their families <…> focus[sing] on family-centered services, individually planned educational programs, and specialized teaching approaches.” (Odom & Wolery, 2003). Also adopts a system-theoretical approach to early intervention with the aim to “describe, analyse and intervene with students from a multidimensional perspective involving both the individual child, the interaction and factors in the environment.” (Björk-Åkesson, Granlund, & Simeonsson, 2005, p. 46).

Family needs
Adopts Simeonsson’s (1996) definition of family needs as seen “as broader expectations reflecting what families expect in the form of supportive services” (p. 205).

Proximal environmental factors
Refers to “specific social, physical, or symbolic contextual characteristics that directly impinge on the child” (Wachs, 2000, p. 125).

Service providers
Denotes all professionals in various sectors providing formal support to children with autism and their families – educational, healthcare, social – from screening and diagnosis to treatment/interventions and other services not limited to addressing the core ASD symptoms only (e.g. respite care, personal assistant, transportation).
Introduction

Children diagnosed with autism spectrum disorders (ASD) demonstrate restricted, repetitive behaviours and interests as well as impairments in social communication and social interaction across multiple contexts (American Psychiatric Association, 2013). To achieve positive learning outcomes in speech, social interaction and communication skills for young children with ASD, it has been recommended using early and intensive behavioural based practices in children’s naturalistic environments such as home and preschools (Bohlín et al., 2012; Odom, 2009; Wong et al., 2014). However, research and practice showed that it is common that children respond differently to evidence-based approaches, demonstrating different learning outcomes with up to 50 percent of children achieving substantial improvements, and the other 50 percent making much slower progress, some showing very limited skill development (McGrew, Ruble, & Smith, 2016; Stahmer, Schreibman, & Cunningham, 2011). This variability in learning outcomes indicates that there is no “one-size-fits-to-all” intervention approach for children with ASD, underscoring the need to individualize intervention programs for each specific child and his/her family. As Stahmer et al. (2011) argue, research should focus on identification of important individual and contextual factors that might influence the effectiveness of a specific intervention for each child. Similarly, McGrew et al. (2016) suggested that research on individualization of treatment protocols for both children and adults with ASD should take into consideration both practitioners’ characteristics, including competence and expertise, and characteristics of the individual with ASD, such as age, gender, autism severity, intellectual and language ability, and medical comorbidities. Moreover, the impact of family and cultural factors including values, preferences, religious beliefs, worldviews, goals and strengths need to be considered.

On an international level, the United Nations (UN) adopted a resolution *Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities* (UN, 67/82, 2012). This document calls upon national governments to focus on “enhancing and increasing research expertise and service delivery, including through international collaboration, by training researchers, service providers as well as non-professionals, in early diagnosis and interventions within health and other relevant sectors” (p. 3). Further-
more, having recognized that worldwide people with ASD and their families are at risk of facing social stigma, isolation and discrimination, the Sixty-seventh World Health Assembly (WHA) adopted a resolution on *Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders* (WHO, WHA 67.8, 2014), where national governments are urged to undertake several actions, among them are:

- to promote sharing of best practices and knowledge about autism spectrum disorders and other developmental disorders;
- to provide social and psychological support and care to families affected by autism spectrum disorders, including persons with autism spectrum disorders and developmental disorders and their families in disability benefit schemes, where available and as appropriate;
- to identify and address disparities in access to services for persons with autism spectrum disorders and other developmental disorders;
- to promote context-specific research on the public health and service delivery aspects of autism spectrum disorders and other developmental disorders, strengthening international research collaboration to identify causes and treatments (pp. 3-4).

In line with the above-mentioned international documents on global efforts to improve quality of life of people with ASD and researchers’ call for individualization of interventions, the present thesis focuses on young children (aged 2-6) diagnosed with ASD and their family members in the cultural context of the Swedish support system. Inspired by theoretical concepts offered by systems theories and the sociocultural view on child development, the thesis presents findings from a research project of a mixed methods design that includes three explorative studies. An array of established and novel qualitative and quantitative data collections tools were employed to address the aims and research questions inherent in the studies.

It is expected that the results of the research presented in this thesis will help bridge gaps between research and practice. More specifically, it will hopefully raise cultural awareness and cultural sensitivity among practitioners, such as preschool teachers, special educators, and healthcare professionals, thus, contributing to their professional competence and improving the situation for families of children with autism. It is hoped that the results of this research will contribute to existing educational and healthcare practices for young children with ASD and their family members – both immediate and extended. Furthermore, it will inform researchers of the need to conduct research which include culture as a relevant variable.
Aim and Objectives

The overarching aim of the present thesis was to identify and describe proximal and distal environmental factors and processes affecting implementation and provision of interventions and services for young children with ASD and their families within the context of the Swedish support system. With a basis in Bronfenbrenner’s theoretical and conceptual framework, proximal environmental factors and processes refer to significant people, objects and symbols, and relationships between them in the child’s nearest settings; while distal environmental factors and processes broadly include cultural group characteristics, values and belief systems at group- and societal levels, and formal and informal support systems.

The specific objectives of the thesis were:

(1) To investigate the scope of reporting ethnicity and other cultural factors in research publications by Swedish scholars involved in empirical research in ASD in children and youth (Study 1).

(2) To explore perceptions of autism, beliefs about its causes, and treatment preferences expressed by parents of young children diagnosed with ASD from culturally, ethnically and linguistically diverse backgrounds (Study 2).

(3) To explore grandparents’ perceived needs in relation to having a young grandchild diagnosed with ASD (Study 3).
System Theories as Theoretical Framework

Theoretical frameworks—assumptions and concepts—play an important role in developmental and family studies (Tudge, Mokrova, Hatfield, & Karin, 2009). Child developmental researchers have underscored the importance of studying culture in addressing needs of children with disabilities as they acknowledged that cultural influences (both differences and commonalities) are important to consider when planning interventions (Bernheimer & Keogh, 1995; Rodriguez & Olswang, 2003). Shonkoff (2000), when emphasizing the significant role that culture plays in child’s development, also pointed to “the need for ongoing methodologically rigorous research in this area” (p. 58). There are several theoretical and conceptual models that specifically incorporate cultural influences on child typical and atypical development. These models have been developed within the systems thinking paradigm that views an individual child as an open system interacting with other systems in the environment(s); and examines how various factors and processes co-vary to produce changes in different systems over time (Wachs, 2000; Yoshikawa & Hsueh, 2001). These models derive from the principles of the general system theory that describe properties of the open system as (1) being in a state of dynamic balance characterised by continual flow and change; (2) being self-regulating and self-organizing, and (3) demonstrating nonlinearity (Capra, 1996; Thelen, 1992). Living systems have complex interactions with other systems on multiple levels in a probabilistic and non-predicatable manner (Thelen, 1992; Wachs, 2000).

Systems theory thinking in relation to family made it possible to suggest and conceptualize “family systems theory” in the 1960s (Dalmau et al., 2017), which views family as a complex social system with its unique features, goals and needs. System theories is the conceptual foundation for the research project described in the present dissertation. Two theoretical models with its emphasis on culture as an environmental factor have guided the present research project: Bronfenbrenner’s bioecological model of human development and Wachs’s multiple-influences model of individual variability.
Bioecological model of human development

One of the most influential theoretical frameworks on child development is Bronfenbrenner’s ecological model of human development (Super & Harkness, 1986). Bronfenbrenner (1979) viewed the concept of culture in his ecological model of child development as an essential element of human development and labelled it as a *macrosystem* that comprises “any belief systems or ideology” (p.26). The idea here is that cultures and subcultures of the given societies greatly influence children’s development and the nature of child-family interactions.

Bronfenbrenner later acknowledged limitations of his proposed framework as lacking dimensions of time to reflect continuity and change in human development over the lifespan. He described the expansion of a new theoretical framework coined “The bioecological model of human development” as the “evolving” process, with the focus of scientific inquiry gradually shifting from the environment to processes over the years (Bronfenbrenner & Morris, 2006, p. 794-795). Thus, within the framework of the bioecological model,

development is defined as the phenomenon of continuity and change in the biopsychological characteristics of human beings, both as individual and as groups. The phenomenon extends over the life course, across successive generations, and through historical time, both past and future (Bronfenbrenner & Morris, 2006, p. 793).

According to Bronfenbrenner and Morris (2006), the bioecological model of human development consists of four main components characterized by dynamic interactions between them. The core component is *Process* that suggests specific ways of interactions between a developing person and his or her environment. Bronfenbrenner called these ways of interactions *proximal processes* and described them as “the primary engines of development” (p. 789). However, as Bronfenbrenner emphasized, the characteristics of the *Person*, of the proximal and distal environmental *Contexts* as well as of *Time* periods when the proximal processes occur, determine the strength with which those processes can influence this person’s development. Bronfenbrenner further described important characteristic features of Person, Context and Time. Three types of Person characteristics that could affect operation of proximal process and, therefore, influence the development over the lifespan are: (1) *dispositions* (or *forces*), (2) *resources* (i.e. abilities, experience, knowledge and acquired skills), and (3) *demand* characteristics. These characteristics are included into the *microsystem* (nested in other systems – from meso- to macrosystems) together with characteristic features of other significant people (family members, teachers, peers etc.), objects, symbols, and where proximal processes occur on a regular basis over extended period of time, thus, shaping Person’s development. The Time di-
mension in the model comprises three consecutive levels labelled as: (1) microtime, (2) mesotime, and (3) macrotime, where microtime refers to sporadic vs. regular occurrences of proximal processes; mesotime – to longevity of these occurrences (in days or weeks); and macrotime – to “the changing expectations and events in the larger society, both within and across generations, as they affect and are affected by, processes and outcomes of human development over the life course” (Bronfenbrenner & Morris, 2006, p 796).

In summary, Bronfenbrenner expanded his earlier framework by adding two important dimensions in his view of child development – the biosystem and the chronosystem. To guide future studies on human development across the lifespan, Bronfenbrenner proposed the operational research design based on his extended theoretical framework referred as the Process-Person-Context-Time (PPCT) model.

Both Bronfenbrenner’s earlier and more recent conceptualizations of child development continue to guide researchers in various disciplines, including the field of ASD research. For instance, based on Bronfenbrenner’s (1979) earlier framework of nested ecological systems, Odom and colleagues (2018) developed an instrument for assessing quality of educational programmes for preschool children (and older students) with ASD – the Autism Program Environment Rating Scale (APERS). Moreover, Bronfenbrenner’s recognition of the importance of child’s biological characteristics and the inclusion of the bio-system into his model is becoming especially relevant in the light of the recent advances in neuroscience in studying brain development and eye gaze patterns as early predictors for ASD (Odom, 2019). Furthermore, Bronfenbrenner’s bioecological model as conceptual framework was most recently applied in the work on the ICF Core Sets for ASD (Mahdi, 2019).

The multiple-influences model

Wachs (2000) proposed a multiple-influences model to explain variability of child development that is built partly on the propositions of the bioecological model of child development (Bronfenbrenner & Morris, 2006) and on the concept of the developmental niche (Super & Harkness, 1986; 1999) that contains three distinctive, but interconnected elements (i.e. subsystems of the niche) that form the cultural environment of the child: 1) the physical and social settings of the child’s life; 2) the culturally regulated customs of child care and child rearing, and 3) the psychology of the caretakers. Wachs (2000) stated: “Individual variability is a necessary consequence of complex interactions among multiple influences that are each necessary but not sufficient contribution to behavior development” (p. 3). In his model Wachs identifies and describes several types of influences that in combination can affect individual’s development. These influences range from distal to proximal as well as from biological to cultural. Wachs (2000) argues that various types
of complex functional or structural linkages (e.g. coactive, interacting, co-varying, causal) among these multiple influences can determine variability in individual developmental trajectories for given outcomes. These influences are briefly summarized below.

Wachs identifies six major classes of influences: (1) evolutionary and ecological; (2) genetic, neural, and hormonal; (3) biomedical and nutritional; (4) phenotypic; (5) proximal environmental; and (6) distal environmental. Evolutionary influences refer to historical developments through selection and inheritance of certain traits at population level, while ecological refer to concurrent physical (and geographical) features, e.g., high latitude and seasonal changes. Genetic, neural, and hormonal influences have “an intra-individual origin” (p.31) and encompass genetic factors (i.e. chromosomal, single- and multiple-gene processes); functioning of the central nervous system, and of the hormonal system (as regulating the individual’s physiological status and internal states). Biomedical and nutritional influences include a range of risk factors such as (a) pre- and perinatal complications related to short gestational age, low and extremely low birth weight in new-borns and associated problems such as a loss of oxygen supply to the fetus and intraventricular haemorrhage; (b) child’s exposure to viral infections at pre- and perinatal stage; (c) child’s exposure to parasitic infection; (d) child’s chronic postnatal illnesses and metabolic disorders; (e) child’s exposure to environmental toxins at pre- or postnatal stage (e.g. maternal alcohol abuse and illegal drug use; lead or mercury exposure); (f) malnutrition, chronic undernutrition, and micronutrient deficits (e.g. iron-deficiency, vitamin C or B deficiency). Phenotypic influences include individual characteristics categorized by Wachs as (a) ‘maturational influences’ (i.e. age-related, intrinsic biological processes named as early physical maturation; functional cognitive maturation, and puberty), and (b) individual biosocial and psychological characteristics such as physical characteristics (e.g., sex/gender, physical size, physical attractiveness, physical disability, facial features); cognitive capacity (e.g., lower or higher IQ); temperament and personality; self-perception, interpersonal styles, and multiple trait combinations (as, e.g., predicting individual resilience or non-resilience to risk factors). In the Wachs’ model, proximal environmental influences comprise of parental beliefs systems (defined as “parent values – the goals that parents see as desirable for their children to achieve – as well as parents’ beliefs and ideas about how their children can achieve these goals” (Luster, Rhodes, & Haas, 1989, as cited in Wachs, 2000, p. 126); parental rearing styles; the child’s social interactions with other children and non-parental adults, and physical properties of the environment where the child is. Distal environmental include such dimensions as cultural and subcultural characteristics (e.g. beliefs, symbols and rituals shared by a group of people; individualistic or collectivistic values); societal institutions; minority status; place of residence (urban or rural), socioeconomic status, societal disruption (e.g. warfare, political violence,
forced migration); parental work situation; children’s schooling (whether they have a possibility to go to school or not), and social support networks.

Wachs (2000) proposed a 4-step operational research design as a research strategy to identify multiple influences for a given outcome and to examine different types of linkage processes (see Figure 1).

**Figure 1. Wachs’ flow chart for steps needed to investigate the impact of multiple, linked developmental influences. Adapted from Wachs (2000), p. 206.**

Thus, for studies included into the present dissertation, the models of child development outlined above are used as guiding theoretical and conceptual framework under the collective term “system theories”. The present project involved steps 1 and 2 of the research design proposed by Wachs (2000).
In addition, one of the studies in this thesis is grounded in assumptions and propositions advanced by the explanatory model of illness/disability (Kleinman, 1980) – the theoretical framework compatible with systems thinking, applicable to the healthcare. It is described below.

**Explanatory Models of Illness or Disability**

According to Kleinman (1980), cultural factors strongly influence people’s perceptions of illness, labelling and explanations of illness, and coping strategies that are based on those explanations. Informed by anthropologic and cross-cultural studies of perceptions of chronic medical conditions, Kleinman, Eisenberg and Good (1978) describe illness as “cultural reactions to disease or discomfort” (p.252). Patient explanatory models reflect cultural and religious beliefs, social class, educational and professional backgrounds, and past experiences with illness and interaction with health care system. Kleinman et al. (1978) argue that professionals and patients or their family members can have different explanatory models of illness which can become either a barrier or a facilitator to joint approaches to health care. In ideal situations, patient’s and professionals’ explanatory models should concur. Professionals’ lack of understanding or inattention to patient’s experiences of illness or disability may lead to patient’s non-compliance and dissatisfaction with care (Kirmayer, 2016).

Kleinman (1980) emphasizes five major aspects of explanatory models of illness or chronic condition: (1) the cause of illness (i.e. aetiology); (2) onset of symptoms; (3) pathophysiology; (4) course of illness (including type and severity of disorder), and (5) treatment. Kleinman notes that patient’s explanatory models may be inconsistent and self-contradictory; furthermore, one and the same patient can have several explanatory models to his/her illness. To elicit patients’ explanatory models, Kleinman (1980) suggested that health professionals ask the following eight questions: (1) What do you think has caused your problem? (2) Why do you think it started when it did? (3) What do you think your sickness does to you? How does it work? (4) How severe is your sickness? Will it have a short or long course? (5) What kind of treatment do you think you should receive? (6) What are the most important results you hope to receive from this treatment? (7) What are the chief problems your sickness has caused for you? And (8) What do you fear most about your sickness?

Kleinman’s framework has laid the ground to development of several cultural assessment instruments, e.g. Explanatory Model Interview Catalogue (EMIC; Weiss, 1997), McGill Illness Narrative Interview (MINI; Groleau, Young, & Kirmayer, 2006) as well as the most recent approach to cultural assessment – the Cultural Formulation Interview (CFI; APA, 2013).
Understanding Autism in Children

Historical and current conceptualizations and description of autism

According to Park et al. (2016), the term “autism” was initially coined by the Swiss psychiatrist Paul Eugen Bleuler to describe behavioural features among individuals with schizophrenia. He derived the concept from the Greek word οὐτός, indicating “self”. In its contemporary sense, an Austrian paediatrician – Hans Asperger – used the definition “autistic psychopathy” to describe a certain behavioural profile in four boys that now is known as “Asperger syndrome” (Park et al., 2016). Parallel, at the beginning of the 1940s the term “autism” was used by Leo Kanner – an Austrian-American psychiatrist – who introduced the concept of “infantile autism” in its modern connotation (Jackson & Volkmar, 2019; Park et al., 2016).

The most recent conceptualization of autism under the umbrella term “autism spectrum disorder” recognizes it as a neurodevelopmental, lifelong condition characterized by core features in two domains: persistent difficulties in social communication and presence of repetitive patterns of behaviour across various contexts (Lord, Elsabbagh, Baird, & Veenstra-Vanderweele, 2018). This conceptualization is reflected in the latest editions of two major diagnostic systems – the Diagnostic and Statistical Manual of Mental Disorders – the Fifth Edition (DSM-5; APA, 2013) and the International Classification of Diseases, the 11th Edition (ICD-11; World Health Organization [WHO], 2019).

Onset, prevalence and aetiology

ASD has its onset in early childhood (typically recognized by age 3) with average age of 18 months. Sex ratio in children with ASD shows that boys are affected more frequently than girls – 3.5:1 (Rutherford et al., 2016), although the most recent research has indicated that girls might be un-identified and underdiagnosed due to differences in behavioural phenotypes (Lawson, 2019). The world population prevalence of ASD is 0.62–0.70% (Lai, Lombardo, & Baron-Cohen, 2014).

ASD has a complex, multifactorial aetiology – neurobiological, genetic, and environmental (Lyall et al., 2017) – characterized by high levels of heritability with a genetic factor estimated 80% (Bai et al., 2019). At present, there are growing number of studies that explore the impact of various envi-
ronmental risk factors at prenatal or postnatal developmental stages such as birth complications; paternal age; exposure to pesticides, pharmaceuticals, heavy metals, chemical and infectious agents, or diets (Interagency Autism Coordinating Committee [IACC] Strategic Plan for ASD, 2017). Although currently there are still gaps in scientific knowledge regarding definite causes of the condition (Amaral et al., 2019), the accumulated research evidence, nevertheless, strongly points to the absence of association between ASD and the measles, mumps and rubella (MMR) vaccines (Hviid, Hansen, Frisch, & Melbye, 2019; Lyall et al., 2017), and it completely disregards the earlier theory of unemotional parenting proposed by Bettelheim (National Institute for Health & Clinical Excellence [NICE], 2012). There are no evidence-based pharmacological treatments yet available that would specifically target the core ASD symptoms; existing evidence-based pharmacological treatments prescribed for children with ASD are mainly symptoms-based and are currently used to address co-existing conditions only (Anagnostou & Brian, 2015; Lord et al., 2018), such as irritability (IACC, 2017) and sleep disturbances (Mandell & Novak, 2005).

Additionally, two features characteristic of ASD – comorbidity and heterogeneity – are important to consider as they can impact diagnostic assessment, research, and, subsequently, clinical practice and educational interventions (Amaral et al., 2019). These concepts are briefly discussed below.

**Comorbidity**
The concept of comorbidity in ASD refers to the presence of co-occurring conditions, or associated, overlapping symptoms (either concurrently or sequentially (Le Courteur, & Szatmari, 2015). These co-occurring conditions can include intellectual disability, eating problems, sleep disorders, behavioural problems, depression, anxiety, epilepsy and presence of genetic or chromosomal disorders (Gillberg, 2010; NICE, 2011; Figure 2). For instance, studies have shown that one-third (31%) of children with autism have a co-occurring intellectual disability (ID) with the IQ score of 70 or less (Christensen et al., 2018). In a recent Swedish population-based study of children with Down syndrome, aside from intellectual disability, 54% had ASD and/or ADHD; of those 22% of children with Down syndrome had a combination of both ASD and ADHD (Wester Oxelgren et al., 2016). A Swedish study on the prevalence rates of developmental disabilities in children with blindness revealed that of all 150 participating children 47 (31%) had also been diagnosed with ASD (de Verdier, Ek, Löfgren, & Fernell, 2017). There are at least two major concerns in relation to co-occurring disorders in ASD mentioned in the literature. As Amaral et al. (2019) noted, there is still limited knowledge in how the core and co-morbid features of ASD are linked to each other, as well as how the behavioural overlap of symptoms affects quality of life of the individual with ASD, and therefore,
Mental and behaviour problems and disorders:
- Anxiety disorders and phobias
- Mood disorders
- Oppositional defiant behaviour
- OCD
- Self-injurious behaviour

Neurodevelopmental problems and disorders:
- ADHD
- Global delay or a learning (intellectual) disability
- Motor coordination problems or DCD
- Academic learning problems, e.g. in literacy or numeracy
- Speech and language disorder
- Tics or Tourette syndrome

Co-existing conditions in ASD

Medical or genetic problems and disorders:
- Epilepsy and epileptic encephalopathy
- Chromosome disorders
- Genetic abnormalities, including fragile X
- Tuberous sclerosis
- Muscular dystrophy
- Neurofibromatosis

Functional problems and disorders:
- Feeding problems, including restricted diets
- Urinary incontinence or enuresis
- Constipation, altered bowel habit, faecal incontinence or encopresis
- Sleep disturbances
- Vision or hearing impairment

Figure 2. Co-existing conditions in ASD. Adapted from Le Couteur and Szatmari (2015) and National Institute for Health and Care Excellence (2011) https://www.nice.org.uk/guidance/cg128. Note: * as classified in the DSM-5.

could contribute to increasing morbidity and reducing life expectancy (Amaral et al., 2019; Hirvikoski et al., 2016). As Gillberg (2010) argues, the co-occurrence of disorders is rather a rule than an exception, and therefore, suggests the term “co-existence” to indicate the overlap of symptoms across neurodevelopmental disorders. This view is supported by other researchers (e.g., Thapar & Rutter, 2015). Other difficulties in relation to comorbidity
expressed in the literature concerns practical challenges that researchers can face in their efforts to identify “cleaner, homogenous samples” (Amaral et al., 2019, p. 706). For instance, Mahdi (2019) described a number of methodological issues in relation to study participants with comorbid diagnoses within the frameworks of the research project on the development of the core sets for ASD and ADHD using the International Classification of Functioning, Disability, and Health (ICF; WHO, 2001).

Heterogeneity
Heterogeneity in ASD refers to a wide-ranging variation in autism phenotypic characteristics (Amaral et al., 2019; Thapar, Cooper, & Rutter, 2017). According to Henry Whitehouse (in Amaral et al., 2019), ASD is heterogeneous in three aspects: (1) aetiological origin, (2) behavioural representation, and (3) expression across the lifespan. (p. 714). As Baron-Cohen (2018) noted, heterogeneity implies a vast disparity in cognitive and language developmental profiles, including presence or absence of co-existing conditions.

Challenges concerning heterogeneity in autism are well recognized, which is reflected now in both the DSM-5 and the ICD-11 that conceptualize autism as a spectrum (Jack & Pelphrey, 2017). Many researchers in the field (e.g., Amaral et al., 2019; Jack & Pelphrey, 2017; Stedman et al., 2019) urge to apply better research methods to be able to describe sub-populations within the spectrum instead of comparing homogenous ASD samples with typically developing groups. Some of these researchers call for a need for integrative research to order to grasp underlying mechanisms behind extreme diversity in autism by studying the influence of both biological and environmental risk and protective factors, as well as by exploring mediating and moderator processes (see, for instance, Janet Lainhart in Amaral et al., 2019). A deeper understanding of heterogeneity in autism may eventually lead to better treatment and support services for individuals with ASD and their family members (Amaral et al., 2019).

Standardized diagnostic tools for ASD
Due to the absence of biological markers for autism, diagnosis of ASD is built on observed child behaviour child and parental reports (Norbury & Spark, 2013). Available standardized diagnostic instruments described as “golden standards for ASD” (Zander, 2015, p.10) are the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 2000) and the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994). The ADOS is the 45-min assessment tool for observing child’s (or adolescent’s/adult’s) behavior suspected for autism and carried out by a qualified clinician (Lord et al., 2018). It is also compatible with another widely researched tool – the ADI-R (Klin, Saulnier, Tsatsanis, & Volkmar, 2005). The ADI-R has a
standardized interview format carried out with child’s caregiver/parents in order to obtain child’s comprehensive developmental history (Lord et al., 2018). The ADI-R is also used for research purposes.

Despite the fact that both instruments are considered to be “gold standards” in diagnostic assessment for ASD, there are, nevertheless, several important concerns described in the literature that should be mentioned. First, both instruments were developed by researchers in the USA and the UK, i.e. English-speaking countries (La Roche, Bush, & D’Angelo, 2018). Harris, Barton and Albert (2014) argued that most diagnostic and screening tools for ASD could be culturally and linguistically biased and, therefore, may not be adequate for diagnosing culturally and linguistically diverse populations in such multicultural context as the USA. These authors examined several ASD assessment instruments, including the ADOS and the ADI-R, for cultural and linguistic adaptation and responsiveness, and found that the majority of the tools did not include samples whose English was not a native language within standardization samples. Moreover, none of the assessments had standardization methods for modifying or adapting test administration for ethnically, culturally and linguistically diverse populations. While some ‘gold standards’ assessment tools for ASD have been translated into other languages, these translated versions require further adaptation and validation in various cultural contexts (La Roche et al., 2018). As van de Vijver, Hofer and Chasiotis (2010) noted, “instruments that have shown good reliability and validity in Western cultures may lose these properties in a non-Western context” (p. 21). Indeed, although it has been widely recognized that many clinical features of ASD are universal across various cultures and socioeconomic groups (Daley, 2004; Grinker, Yeargin-Allsopp, & Boyle, 2011; Lord et al., 2018; Wallace et al., 2012), these features can manifest differently in various cultures (Rutter & Nikapota, 2006). For instance, Bello-Mojeed et al. (2014) described that African children with ASD did not always demonstrate stereotypical behaviours such as hand flapping and rocking, and that the majority of these children were non-verbal. Moreover, identification of children with ASD in low- and middle-income Asian or African countries can be challenging due to comorbidities and neurological complications resulted from children’s exposure to infectious diseases at early ages (Bello-Mojeed et al., 2014; Srinath & Jacob, 2016). Thus, well-established standardized assessment tools for ASD, such as ADOS or ADR-R may not be sensitive enough to capture these aspects outside Northern or Western Europe (Abubakar, Ssewanyana, de Vries, & Newton, 2016).

As a result of using culturally non-responsive diagnostic assessment instruments within the contexts of Western societies, children from diverse cultural and linguistic backgrounds can be misdiagnosed, underdiagnosed or over-diagnosed (Harris et al., 2014), which in its turn can affect delivery of intervention services. For instance, Norbury and Sparks (2013) described some of these challenges in assessment and intervention services for children
with ASD and specific language impairment and their families living in the London borough of Hackney in the UK – the community where approximately 100 different languages are spoken by its residents, and where many households observe traditional male-female roles. The major challenges for practitioners reported in the study included (a) the absence of standardized tests in the languages spoken in the region (as they existed only in English), (b) difficulties to find educated bilingual professionals, and, among other, (c) children’s unfamiliarity with dolls and plastic toys as they did not have experience of playing with such toys at home. Some families did not implement intervention programmes that involved pretend play or following child’s lead in play as it was culturally incompatible for adults to play with children or it was not possible to do so due to the family circumstances. Some families chose not to participate in intervention programs because of their cultural or religious beliefs (Norbury & Sparks, 2013). Similar findings from Sweden were reported by Andersson and Jansson (2007) who investigated experiences of speech-language pathologists (SLPs) of working with multilingual immigrant children with ASD. According to the SLPs, a problem that existed in Sweden was that assessments were done primarily in Swedish with the assessment instruments tailored to children from the dominant culture, i.e. Swedish. Participants pointed out that there was a strong need to increase the amount of multilingual and culturally competent professionals. All participants in this study agreed that in order to for a child to achieve positive language development, professionals should tailor their interventions to family’s situation in its entirety, taking into consideration which kind of languages were spoken in the family, and how these were used in child’s everyday life.

The Importance of Family

Anthropological research have showed that in some non-Western cultures a definition of family is distinct from a Western (including Swedish) view that encompasses mainly nuclear family members (Weisner & Fiese, 2011). In many collectivistic cultures “family” can have a wider definition. For instance, in the Somali culture, family may include not only blood-related family members such as extended family but also people included into kinship network, e.g. members of the same tribe or clan (Wolf et al, 2016), or other children as a result of transnational mobility (Mohme, 2016). Therefore, in the present thesis the following definition of family provided by the Division for Early Childhood (2015) has been adopted:

A family is defined as two or more people who regard themselves as family and who carry out the functions that families typically perform. This means that people who are not related by birth, marriage, or adoption and who do not reside together may be a family unit if they regard each other as family and if
they jointly carry out the functions that are typically assumed by families. Parental roles may include a single parent, grandparents as parents, two parents of the same sex, and other constellations that differ from the traditional mother-father roles. In addition to parents, families are comprised of siblings and the full range of extended family, including grandparents, aunts/uncles, and cousins (p.8).

**Family characteristics**

Family characteristics are seen as an important variable that affects intervention outcomes for their child with ASD, e.g., ethnicity, race, cultural identity, attitudes to disability, marital status, parents’ gender, educational and socioeconomic background and migration (Magnusson et al., 2012; Mandell & Novak, 2005; Stahmer et al., 2011). Research studying the impact of these variables on effectiveness of intervention for children with ASD shows that families’ perceptions of the disability within a certain cultural context can contribute to understanding of families’ access to various educational and health care services, their appraisal of autism as well as social support patterns (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). It has been also recognized that cultural backgrounds of families with children with ASD can influence families’ decision to participate in various types of interventions for their children (Mandell & Novak, 2005).

In addition, it appears that there is a shortage of professionals competent in working with culturally and ethnically diverse children with ASD (Irvin et al., 2012; Hughes Fong et al., 2016; Tincani et al., 2009), which points to a strong need to educate practitioners in order to meet individual needs of children and their families. As Tincani et al. (2009) noted, in the US context, there is limited data available to help practitioners ensure that culturally appropriate services were provided to children with ASD with culturally and ethnically background as research in special education had been predominantly done with Anglo population. Solid knowledge among professionals on families’ cultural values and beliefs, perception of their children’s disability, interactional patterns as well as knowledge on differences in language and communication practices in various ethnical groups including bilingual families would clearly contribute to developing individualized intervention programs (Dyches et al., 2004; Mandell & Novak, 2005; Yu, 2013) both in Sweden and internationally.

**Intergenerational support: grandparents’ needs and experiences of having a grandchild with ASD**

Grandparents today generally experience better health and live longer. In a family system where a child with disability is present, grandparents’ role in supporting their grandchild and adult children is increasing (Dougherty, 2009). Studies show that grandparents of children with disabilities or chronic conditions may experience double grief or even triple grief (Klasén McGrath, 2008): for their own adult child, for their grandchild, and their
own sorrow with feelings of guilt and injustice that it happened to their family. Internationally available research on grandparents of children with ASD is very limited (Hastings, 2008; Hillman, 2007; Margetts, Le Courteur, & Croom, 2006). For instance, in a UK-based study, grandparents described themselves as being parents to both to their own adult child and a grandchild, although with some admitting feeling the double burden of taking care of two generations (Margetts et al., 2006). Grandparents’ experiences were also described as “striving for answers”: they often struggled with the questions on how much they could help their adult children; or looking for answers on a possible cause of the disorder. A US-based study (Hillman et al., 2017) reported that grandparents made substantial accommodations to support their grandchildren with ASD: babysitting, providing transportation and engaging in teaching their grandchildren skills using various strategies. The results also pointed that grandparents coped fairly well in relation to their grandchild’s ASD although they expressed lots of worries for their adult children raising their grandchild.

Research indicates that grandparents may have their own needs concerning their grandchild’s autism: they may seek information on the child’s condition and may seek social support to deal with stressors in the family (Hillman, 2007). Grandparents can have powerful emotional reactions to the diagnosis of ASD (Kahana et al., 2015). Engaging into one-to-one interactions with the child with ASD may require using physical strength for grandparents, which present more problems for them. To date, however, there is a paucity of research available that would explicitly describe unique needs of grandparents of young children with ASD, which currently presents a significant gap in the literature.

Culture

According to the American Psychiatric Association (2013), culture is defined as

... systems of knowledge, concepts, rules, and practices that are learned and transmitted across generations. Culture includes language, religion and spirituality, family structures, life-cycle stages, ceremonial rituals, and customs, as well as moral and legal systems. Cultures are open, dynamic systems that undergo continuous change over time; in the contemporary world, most individuals and groups are exposed to multiple cultures, which they use to fashion their own identities and make sense of experience (DSM-5, 2013, p. 749).

Wachs (2000) points to a heterogeneous nature of culture, and underlines the importance of considering intra-cultural variability in studying human developmental outcomes. Kagawa Singer et al. (2016) noted that when defining culture, a distinction should made between what culture is and what cul-
ture does. Culture, according to the authors, is “a constantly evolving, multidimensional, multi-level process” that encompasses all aspects of the human condition” (p. 6, emphasis as in original). What culture does is “to enable us to interpret the worlds in which we live through beliefs, attitudes, practices, and spiritual and emotional explanations that we use to create norms of ways of being in social institutions to codify these norms.” (p. 6). These cultural tools and processes promote survival and wellbeing of group members. Several authors argue (Kagawa Singer, Dressler, George, & Elwood, 2014; Kagawa Singer et al., 2016) that over the past years culture has been conceptualized as a static notion and has been predominantly operationalized by using a number of simplistic proxies – either nominal dichotomies based on the notions of race and/or ethnicity (e.g., non-Hispanic White/African-American, Japanese), or stereotypical beliefs (e.g., fatalism, familismo). This approach to culture can be misleading for understanding factors affecting behavioural patterns at various levels – individual-, group-, and societal. Researchers’ use of nominal variables as proxies to describe cultural characteristics of their study participants in statistical analyses can produce unreliable findings, or cannot always provide satisfactory explanations to observed differences in health outcomes (Kagawa-Singer et al., 2016). Moreover, research has mainly focused “on the individual without accounting for the influence of the social, historical, and environmental context of the group(s) to which s/he belongs” (p. 3). These challenges in the use of culture in research consequently contribute to health disparity.

Importance of studying culture as a distal environmental factor influencing child development has been particularly recognized within the field of child psychopathology. For instance, based on the extensive review of available literature, Wachs (2000) argues that cultural, subcultural, and social class characteristics can influence parental beliefs, their values, goals, and behavioral norms, which can affect child rearing practices and child outcomes. Besides, cultural and subcultural beliefs and values, social class or minority status can “lead to different groups of individuals having differential accessibility to resources” (p. 169). In order to understand differences in human behavior and to be able to tackle existing inequalities and inequities among various populations, Kagawa-Singer et al. (2016) called for an integration of strong theoretical frameworks across several science disciplines – social, behavioural, health care, public health – where the concept of culture could be used in a more accurate and effective way.

**Ethnicity**

The United Nation (2017) defines ethnicity in relation to population census as follows:

Broadly defined, *ethnicity* is based on a shared understanding of history and territorial origins (regional and national) of an ethnic group or community, as
well as on particular cultural characteristics such as language or religion. Respondents’ understanding or views about ethnicity, awareness of their family background, the number of generations they have spent in a country, and the length of time since immigration are all possible factors affecting the reporting of ethnicity in a census. Ethnicity is multidimensional and is more a process than a static concept, and so ethnic classification should be treated with movable boundaries. (p. 204).

A similar, however, somewhat extended definition of ethnicity is provided in the DSM-5 (APA, 2013):

*Ethnicity* is a culturally constructed group identity used to define peoples and communities. It may be rooted in a common history, geography, language, religion, or other shared characteristics of a group, which distinguish that group from others. Ethnicity may be self-assigned or attributed by outsiders. Increasing mobility, intermarriage, and intermixing of cultures has defined new mixed, multiple, or hybrid ethnic identities. (p.749).

In Sweden, the earlier Swedish legislation – the Personal Data Act (1998:204) prohibited collecting information on sensitive personal information such as ethnicity, and therefore, Sweden-based researchers tend to use country of origin as a proxy for ethnicity operationalized in a number of different ways, e.g., (1) the dichotomization of native/immigrant, (2) the immigrant’s income level in their country of origin (native, OECD-country, non-OECD-country), and (3) different clusters of country or area of origin (Hollander, 2013). However, the Personal Data Act (1998:204) permitted collecting and processing information on ethnicity and culture for research purposes if the researchers clearly described strategies for protecting identities of their research participants in their research protocols to ethics review boards. The recent EU Regulation on General Data Protection (GDPR 2016/679) that substituted the Personal Data Act as of the 25th May 2018 also allows collecting and processing sensitive personal information related to individual’s cultural factors, such as ethnicity and religion.

Of interest, the current work on statistical systems in Sweden regarding the United Nations (UN) 2030 Agenda and its 17 Sustainable Development Goals is based on already existing dimensions for collecting data on ethnicity, i.e. on proxies for ethnicities. As the Deputy Director at Statistics Sweden Dr. Viveka Palm pointed out (personal communication, January, 2018), the official statistical systems did not intend disaggregating data by ethnicity any further than what is currently in use. Indeed, according to the UN principles and recommendations for vital statistics (2014), it largely depends on countries themselves how data on ethnicity are to be collected given the sensitive nature of information asked.

In official public documents, the terms ‘foreign origin’ (*utländsk bakgrund*) and ‘Swedish origin’ (*svensk bakgrund*) are used (Farkas, 2017).
Statistics Sweden (n.d.) provide the following definitions: persons with Swedish background are those who were born in Sweden with both parents born in Sweden, or when one parent born in Sweden and the other born outside Sweden. Persons with foreign background are those who were born outside Sweden, or persons who were born in Sweden, whose both parents born outside Sweden.

**Race**
The CFI (DSM-5; APA, 2013) includes the concept of ‘race’ defined as “a culturally constructed category of identity that divides humanity into groups based on a variety of superficial physical traits attributed to some hypothetical intrinsic, biological characteristics” (p. 749). In some countries, e.g. the USA, the concept of ‘race’ in research is used to describe characteristics of study participants using specific descriptors, e.g. ‘African American’, ‘Asian American’, ‘Hispanic/Latino’, ‘Caucasian/White’. In Sweden, however, the concept of ‘race’ is not used as it is considered as socially constructed (Bäärnhielm, 2014), and is closely connected to racism (Farkas, 2017). Therefore, in the Swedish translation of the CFI the word ‘race’ was changed into ‘appearance’ referring to an individual’s phenotypical features (S. Bäärnhielm, personal communication, 9 October, 2016). Other researchers (e.g. Mohme, 2016) noted that a term ‘visible minorities’ can also be in use to refer to ‘non-white people’ (p. 22). As Mohme (2016) argued, in Sweden the word ‘race’ is “almost taboo, a sensitive subject, and often replaced by ethnicity, or culture, or even religion” (p.22).

**Treatment and Intervention Approaches**

**Evidence-based practices (EBPs)**
Evidence-based practices (EBPs) for ASD are recommended as the first line of interventions to be used with children with ASD and their family members due to strong empirical evidence of demonstrating positive outcomes for specific goals (IACC, 2017). The concept of EBPs dates back to work of Archie Cochrane, an epidemiologist from the UK, who promoted the use of EBPs to inform clinical practice (Reichow, 2016). The original (expanded) definition of EBPs in medicine was provided by Sacket, Straus, Richardson, Rosenberg, and Haynes (2000, as cited in Reichow, 2016, p. 2): “the integration of best research evidence with our clinical expertise and our patient’s unique values and circumstances”. In various disciplines the concept of EBPs is defined and operationalized somewhat differently (Reichow, 2016; Smith, 2013). For instance, American Psychological Association (2006) defines evidence-based practice in psychology (EBPP) as “the integration of the best available research with clinical expertise in the context of patient characteristics, culture, and preferences.” (p. 273). In the field of early inter-
vention/early childhood special education, McLean, Sandall and Smith (2016) operationalize EBPs as a combination of “research evidence with family and professional experiences and values to generate practices which would lead to best outcomes for young children with disabilities” (p. 17). Professional literature on EBPs in interventions for children with ASD distinguishes between two types of intervention practices: focused interventions and comprehensive treatment models (CTMs) (Odom, Boyd, Hall, & Hume, 2010; Odom et al., 2010; Wong et al., 2014; 2015).

**Comprehensive treatment models**

Comprehensive treatment models (CTMs) are defined as a set of practices (programs) designed for children with ASD and their family members to have an impact on a broad range of development areas affected by ASD (Odom, Boyd, Hall, & Hume, 2014). According to Odom et al. (2014), CTMs have five important characteristics: (1) include practices “to affect change in multiple developmental or skill domain” (p. 770); (2) have a clear conceptual or theoretical framework; (3) have a treatment guide or a manual; (4) require intensity of more than 25 hours per week and longevity of more than one year’s time period, and (5) have a description in a published book, a book chapter or in a journal article. Some of the CTMs are well-established and have a long history. Examples of evidence-based CTMs are the Early Intensive Behavioral Intervention (EIBI) derived from the Lovaas model, the Early Start Denver Model (ESDM), the Pivotal Response Treatment Walden model, and the LEAP model (Odom et al., 2010; Odom et al., 2014). The above mentioned CTMs have underlying teaching frameworks based on the principles and procedures of applied behavior analysis (ABA) and typical child development, using various types of assessment evaluation protocols, typically implemented in preschool/school and/or home settings, several of which combine discrete trial teaching and naturalistic teaching formats. The EIBI for young children with ASD are implemented in preschools and through health care disability services (known as child habilitation centres) (Långh, 2017; see also Klintwall & Eikeseth, 2014). The Early Start Denver model (ESDM) was designed for very young children with its conceptual framework combining the ABA-based and developmental and relationship-based approaches. The model has been highlighted as efficacious in the recommendations by the heads of habilitation centers in Sweden (Bohlin et al., 2012). Indeed, as the review study by Zwaigenbaum et al. (2013) has shown, the Early Start Denver model was one of the two CTMs (alongside the Lovaas model) that demonstrated evidence of significantly improved outcomes compared to control groups after treatment longevity of 8 weeks to 2-3 years.
Focused interventions

Focused (or targeted) interventions are defined as “individual instructional practices or strategies that teachers and other practitioners use to teach specific educational targets – skills and concepts – to children with ASD” (Odom et al., 2010, p. 276). They address specific learner outcomes, tend to occur over a shorter time period than CTMs (i.e., until the individual goal is achieved), and can be integrated in CTMs (Odom et al., 2010), usually consisting of a set of procedures which a skilled practitioner adapts to meet a specific learning goal (Smith, 2013) e.g., teaching imitation through video-modelling using visual supports, reinforcement, and prompt fading.

The work on the identification of focused EBPs for children and youth with ASD, carried out by two independent, US-based research groups, has been especially important. These are the National Standards Project (NSP) at the National Autism Center (NAC) and the National Professional Development Center on ASD (NPDC) (Wong et al., 2014). Both groups independently of each other conducted systematic reviews of literature on non-medical interventions (treatments) used for children and youth with ASD (aged < 22 years) (Sam et al., 2019) and identified a number of practices reported over extended periods of time. For instance, the NSP identified 14 established CTMs and focused intervention types of treatment for children and youth (aged < 22 years) (NAC, 2015) that showed sufficient evidence to be regarded as effective. The NPDC group initially identified 24 EBPs (Odom et al., 2010) that later were extended to 27 focused evidence-based interventions targeting specific learning goals (Wong et al., 2014; 2015). Currently both research groups are working on extending their practice based research reviews to incorporate literature published after these studies appeared.

The emergence of the EBPs has become an important step forward in addressing the needs of children with ASD in various settings – educational, social and healthcare. However, there is a significant limitation concerning identified EBPs: the results of the efficacy studies in ASD interventions might not always be generalizable to culturally diverse children as the majority of these studies had been conducted predominantly with White/Caucasian children (West et al., 2016).

Complementary and alternative medicine (CAM)

Complementary and alternative medicine (CAM) are defined by Cochrane Collaboration as “a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period” (Wieland, Manheimer, & Berman, 2011, p. 4). Furthermore, the National Center for Complementary and Integrative Health (NCCIH; U.S. Department of Health and Human Service), previously known as the National Center for Comple-
mentary and Alternative Medicine (NCCAM) distinguishes between complementary and alternative as two different concepts of non-conventional approaches to healthcare. The NCCIH further categorizes complementary practices into several types such as ‘natural products’ (e.g. vitamins and minerals, herbal and dietary supplements) ‘mind-body practices (e.g. acupuncture, massage, yoga, qi gong), and ‘other complementary health approaches’ (e.g. Ayurvedic medicine, traditional Chinese medicine, homeopathy).

Research on treatment effectiveness of CAM for children with autism has not yet yielded sufficient information to consider some practices as evidence-based or established. For instance, the National Standards Project (2015) identified massage therapy and music therapy as emerging, and gluten-free and casein-free diets as unestablished practices. Recent studies have showed that these types of CAM are most likely to be widely used by preschool-aged children with ASD. For instance, a mixed methods study by Lindly, Thorburn, Heisler, Reyse, & Zuckerman (2018) revealed that nearly half of the children (44.9%) who participated in the study reported using most frequently such ‘natural products’ practices as vitamins, herbal supplements and special diets. The interview results specified further the type of CAM used by these children: the most frequently used diets were gluten and/or casein free diets; other most often used practices included massage therapy, yoga, and qi gong as part of the ‘mind and body’ approach. In another study, Rubenstein and colleagues (2018) specifically investigated the prevalence of the use of gluten-free diet among preschool children with ASD (age range of 30 to 68 months). Their findings demonstrated that at the time of the study, 11.1% participants reported using gluten-free diet and 20.4% reported they had ever used it. The results also showed a strong relationship between the use of gluten-free diet and gastrointestinal problems; however, the researchers could not assess the effectiveness of the diet for either ASD symptoms or gastrointestinal concerns (Rubenstein et al., 2018). In general, these studies support findings reported in earlier studies on the use of CAM by children with ASD (Goin-Kochel, Myers, & Mackintosh, 2007; Green et al., 2006; Hanson et al., 2007; Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Wong, & Smith, 2006). Another shared result for both earlier and more recent studies is insufficiently strong evidence of treatment effectiveness of complementary treatment practices such as dietary therapies or nutritional supplements for core ASD symptoms (Sathe et al., 2017).

Several authors had long ago called for a need for investigating parents’ help-seeking behaviors and decisions they make for intervention strategies for their child’s autism (Daley, 2004; Mandell & Novak, 2005). As Lindly et al. (2018) note, it is important to study parental use of CAM for children with ASD as a) they are commonly used by the parents; b) many CAM practices and modalities lack sufficient evidence of efficacy or safety, and c) can be very expensive for families, especially for those from low-income back-
grounds. Indeed, as studies showed, alongside the use of evidence-based practices or emerging practices (e.g. massage or music therapy), parents can also seek out ineffective or even harmful treatments, such as chemical chelation as detoxification strategy or hyperbaric oxygen therapy (Levy & Hyman, 2008). For instance, studies showed that 9-10% of children diagnosed with autism (age range 1.7-21.9) used chelation clathration (Goin-Kochel et al., 2007; Green et al., 2006).

Researchers have also argued that parents’ decisions to use CAM might be linked to parents’ conceptualizations and explanations of the disorder and its symptoms onset (Goin-Kochel, Mire, & Demsey, 2015). Indeed, earlier studies had documented that parents’ use of CAM is directly related to their beliefs about possible causes of autism (e.g., Harrington, Rosen, Garnecho, & Patrick, 2006). Mandell and Novak (2005) suggested that the use of various non-conventional treatment strategies could be at least partly attributed to “the interplay of culture and communities’ ASD-related resources” (p.113), thus, calling for a more nuanced approach in research to disentangle relationships between culture and treatment choices that parents use for their children. Within the European context, a study by Salomone et al. (2015) on the use of CAM for young children with ASD showed that nearly half (47%) of all participating parents from 18 European countries reported using at least one CAM in the last 6 months; among them 24% reported using nutritional supplements and diet therapy (e.g., vitamins and gluten- or casein-free diets); 23% reported using mind-body practices (e.g., sensory integration therapy and massage), while 2.4% of parents across all countries reported using potentially harmful practices. In this study, the use of CAM was associated with parents’ higher educational level. The researchers also found geographical differences in the prevalence of using CAM with parents residing in the countries of Eastern Europe reporting significantly higher rates of non-conventional practices (66%) for their children. These parents also reported significantly higher rates of diet therapy, mind-body practices as well as use of use of unsafe practices compared to the parents from countries in Northern, Western and Southern Europe. Parents from Northern Europe reported higher rates of using diet therapy and mind-body practices compared to parents from Southern or Western Europe (Salomone et al., 2015). Interestingly, in this study, parents from Sweden were not represented in the ‘Northern group’ cohort. As of date, there are yet no published studies available that would specifically investigate families’ use of CAM for their young children diagnosed with ASD in the context of Sweden.

In summary, the literature on the parental use of CAM for their children with ASD suggest that child’s young age and severity of symptoms as well as parental greater educational level is associated with higher level of the CAM use (Green et al., 2006; Lindly et al., 2018; Salomone et al., 2015). Child characteristics (age and severity of ASD) could also explain the multitude of treatment that parents choose for their children (Green et al., 2006).
In addition, there is still a need for studies to investigate relationships between cultural factors and families’ treatment choices for their children in the context of Northern European countries, including Sweden.

**Challenges in ASD intervention research**

According to Stahmer et al. (2011), most efficacy studies on ASD do not always provide enough information on participants’ demographic characteristics, e.g. ethnicity, race and socioeconomic background despite recommendations to clearly specify selection criteria and descriptions of research participants to ensure replicability and generalizability of study results (Kistner & Robbins, 1986, Zwaigenbaum et al., 2015). For instance, Odom et al. (2014) reviewed 30 articles reporting efficacy of interventions and instructions using technology for adolescents and young adults with ASD and found that only three articles included racially diverse participants and none of the reviewed articles reported linguistically diverse participants. Similarly, Wong et al. (2014; 2015) noted that the reviewed literature on focused intervention practices for ASD rarely included demographic information on race, ethnicity and cultural diversity or socioeconomic status of children or their families. The review study by the NSP (2015) reported findings consistent with those reported by Wong et al. (2014), i.e. many studies, particularly, those using single-case research design did not report data on race or ethnicity of their study participants.

To evaluate methodological practices for reporting ethnicity for research participants, Pierce et al. (2014) conducted a comprehensive literature review of ASD research published in three academic journals: Autism, Focus on Autism and Other Developmental Disabilities, and Journal of Autism and Developmental Disorders (JADD). They reviewed 943 studies and found that 72% of the reviewed articles did not include ethnicity or other descriptors (e.g. racial or cultural differences) for research participants. The researchers also found that when ethnicity was reported (n=138 studies), 54% of these studies (n=64) did not include ethnicity or race variable into data analysis. Another important finding was that 40.5% studies that did report ethnicity/race of research participants identified their samples as small or limited ethnic minority, which raises the issue of generalizability and replication of study outcomes across different or similar ethnic groups. It was also unclear, according to Pierce et al. (2014), if small numbers of ethnic minorities with ASD who participated in these studies was due to their unwillingness to take part in research or if participants simply were not recruited for participation. Based on the results from their literature review, the authors strongly encourage ASD researchers to report the ethnicity of research participants in their studies to be able “to compare, replicate, and generalize their findings” (p. 1516).

With the aims to extend Pierce et al.’s (2014) study and to address limitations noted by Wong et al. (2014), West and colleagues (2016) examined the
research articles included into the review study by NPDC on EBPs to understand participants’ cultural characteristics, such as race, ethnicity or nationality. The researchers found that of 2,489 participants in the 408 studies reviewed by Wong et al (2014), 31% (n=770) had reported cultural characteristics; of these participants the majority 63.5% (n=489) were described as White, European American, or Caucasian. Within the European context, Magán-Maganto et al. (2017) revealed in their review study that European ASD scholars did not investigate adequately socio-economic and cultural characteristics of their study participants and the role these factors might affect families’ access to services. In sum, these findings confirm the results reported by Pierce et al. (2014) and raised justified concerns for the field of special education regarding the use of identified evidence-based practices for ASD. West et al. (2016) noted: “The absence of rigorous studies with diverse participants may compromise confidence about the efficacy of these EBPs” (p.160). Zwaigenbaum et al. (2015) argued that involving culturally diverse participants into intervention research can facilitate understanding of effects of family factors on outcomes of treatment approaches. Furthermore, as Pierce et al. (2014) argue, reporting of ethnicity and cultural factors in future ASD research will help understand mechanisms underlying disproportionate diagnosis and access to services for ethnic minorities with ASD, which may improve outcomes for these individuals and their families. Indeed, disparities between minority and majority populations in multi-national communities in accessing diagnostic and intervention services are well described in ASD research literature (Grinker et al., 2011; Mandell et al., 2009; NAC, 2015). For instance, research conducted in the USA, indicate that culturally, ethnically and racially diverse children with ASD have a tendency to be under-identified and diagnosed later in comparison with White children and, therefore, get delayed access to health care services and eligibility for special education services (Tincani et al., 2009). As Mandell et al. (2002) argue, this could be reflective of family and community factors, e.g. parents’ beliefs about ASD, knowledge of ASD, lack of health literacy, and logistical issues such as limited access to child care due to difficulties with transportation. Among other factors that could be associated with underrepresentation of children with ASD diagnosis with culturally and ethnically diverse backgrounds are families’ poverty, low levels of education and employment, and fear of deportation due to illegal immigration status (Tincani et al., 2009).

The role that researchers play in generating scientific evidence is crucial in shaping policy, practice and public debate regarding disparities (Mir et al., 2013). To help to reduce existing disparities in accessing high quality intervention practices based on research evidence, researchers have been encouraged to apply a set of principles to guide design, conduct and reporting of research that involves diverse populations. For example, suggested guidelines on quality of social research on ethnicity and health encompass the
following aspects: clear conceptualization and operationalization of ethnicity variable; strategic sampling strategy, rigorous measurement and analysis, cautious interpretation of data, and accurate presentation and dissemination of findings (Salway et al., 2009; Salway et al., 2011). Other examples include the ten core inter-disciplinary principles for research on ethnicity and health known as the Leeds Consensus Statement (Mir et al., 2013), and, the GAP-REACH checklist to assess the scope of reporting of cultural factors in psychiatric research publications developed by Lewis-Fernández et al. (2013).

Despite these advances, several authors pointed to a number of methodological challenges. For instance, Zwaigenbaum et al. (2015) noted that it could be difficult to recruit culturally diverse families with young children with ASD into intervention research as they might not be willing to participate in these studies due to cultural beliefs and attitudes about child rearing styles, stigma toward developmental delays, or language barriers. Therefore, the authors highlighted a need for researchers “to make a particular effort to recruit as culturally diverse a research sample as possible” (Zwaigenbaum et al., 2015, p.S76). West et al. (2016) maintain that the use of qualitative and mixed methods designs can help investigators to meet at least two goals: (1) to understand reasons behind parents’ reluctance to participate to be able to improve recruitment strategies and retention of culturally diverse participants in ASD intervention research, and (2) to gain a deeper knowledge about the ways cultural factors might influence implementation of evidence-based, special education practices. Among other challenges in ASD research described in the literature are autism’s constantly changing conceptualizations and definitions and reliance on diagnostic and categorical labels for ASD (Amaral et al., 2019; Karts & Van Hecke, 2012). These issues are briefly described below.

Clinical definitions of autism in DSM and ICD over time

In the field of biomedicine with its roots in a Western medical tradition (Kleinman, 1995), the evolution of conceptualization and definition of autism can be traced from Kanner’s (1943) classic report on 11 children with autism to two diagnostic systems mentioned earlier – the DSM and the ICD (Volkmar & McPartland, 2014). The dynamic and evolving nature of autism as the diagnostic concept over time in both classifications is presented in Table 1. However, advances in research by the late of the 1970s required better definitions of autism (Jackson & Volkmar, 2019). As a consequence, Rutter (1978) proposed a behavioural definition of autism based both on Kanner’s clinical description of 11 cases and his own clinical work and research with children with developmental disabilities:
the definition of childhood autism in terms of four essential criteria in relation to the child’s behaviour before age 5 years still seems to be the best procedure. The four criteria are (1) an onset before the age of 30 months, (2) impaired social development that has a number of special characteristics and is out of keeping with the child’s intellectual level, (3) delayed and deviant language that also has certain defined features and is out of keeping with the child’s intellectual level, and (4) insistence on sameness, as shown by stereotyped play patterns, abnormal preoccupations, or resistance to change. (p. 156).

Rutter’s combination of Kanner’s initial definition of autism and research findings accumulated by the late 1970s, which confirmed the validity of autism, was an important contribution to clinical definition of autism (Jackson & Volkmar, 2019). This combination was reflected in the third edition of the DSM – DSM-III – where ‘infantile autism’ was included as a separate disorder for the first time under the a new group of disorders – the Pervasive Developmental Disorders (PDD; Volkmar, Cicchetti, Bregman, & Cohen, 1992; Volkmar & McPartland, 2014). Besides, with the publication of the DSM-III and introduction of the PDD group, autism was recognized as a condition distinct from childhood schizophrenia or other psychoses (Le Couteur & Szatmari, 2015). However, as Volkmar and McPartland (2014) noted, the overall approach to definition and diagnosis of autism was monothetic, i.e. required every diagnostic criterion be met, and therefore, was regarded as inflexible; moreover, it did not consider children’s developmental trajectories. These issues led to consequent revisions in diagnostic criteria for autism, which were addressed in the DSM-III’s revised version, DSM-III-R (Volkmar et al., 1992). The revised classification provided a polythetic definition of autism meaning that of 16 diagnostic criteria in three domains (social, communication/play, and restricted behavior) at least 8 criteria had to be met, two of which would be social, and at least one criteria had to be from the other two domains (Jackson & Volkmar, 2019; Volkmar & McPartland, 2014) (Table 1). Although this new, broadened diagnostic concept of autism did pay attention to children’s developmental change, with time it became evident that the use of the DSM-III-R’s criteria over-diagnosed autism (Volkmar et al., 1992; Volkmar & Reichow, 2013) and did not necessarily include information on early onset, but attending more to examination of current situation (Volkmar & McPartland, 2014).

Clark, Cuthbert, Lewis-Fernández, Narrow and Reed (2017) noted that the development of both the DSM-III and its revised version, the DSM-III-R, practically did not include international input and involved only little collaboration with WHO. However, the subsequent DSM edition – the DSM-IV – and the tenth version of ICD – the ICD-10 – were marked with close collaboration among the work groups for both classifications, which resulted in similar conceptualizations of psychopathology in general (Clark et al., 2017) and of autism, in particular (Volkmar & Reichow, 2013). The convergent
efforts to conceptualization of autism, described as a “major breakthrough” (Jackson & Volkmar, 2019, p. 5), culminated in a polythetic definition of autism and inclusion of three recognized disorders: Asperger’s disorder, Childhood Disintegrative disorder (known earlier as Heller syndrome), and Rett’s disorder (Jackson & Volkmar, 2019) (Table 1). Both the DSM-IV and the ICD-10 retained three categories of impairments consistent with the DSM-III-R (Volkmar & Reichow, 2013). Also consistent with the previous DSM edition, the DSM-IV retained the subthreshold category – pervasive developmental disorder not otherwise specified (PDD-NOS) to describe cases of conditions indicative of autism but not fulfilling diagnostic criteria for autism; a corresponding category in the ICD-10 was the diagnosis of “atypical autism” (Volkmar & McPartland, 2014). Thus, both diagnostic systems can be characterized by the inclusion of several autism subtypes under the umbrella term “pervasive developmental disorders” (Le Couteur & Szatmari, 2015).

Subsequent advances in clinical research and genetic studies revealed several issues that needed to be addressed. First, there was a scarce evidence in clinical distinctions among various subtypes of pervasive developmental disorders (Le Couteur & Szatmari, 2015). For instance, concerns were raised regarding the definition of Asperger syndrome, which resulted in re-writing of the description of the disorder in the DSM-IV-TR, although retaining its diagnostic criteria (Volkmar & McPartland, 2014). According to the authors, research had showed that these criteria lacked stringency, and were used inconsistently across various clinical settings. Moreover, studies that applied more rigorous approaches to diagnosis suggested possible distinctions between Asperger’s disorder and high-functioning autism regarding clinical presentation, prognosis and interventions (de Giambattista et al., 2019; Volkmar & McPartland, 2014). Second, there were concerns regarding the subthreshold condition termed PDD-NOS in the DSM-IV as this diagnostic category accidentally overlapped with an older diagnostic category of “atypical personality development” (Jackson & Volkmar, 2019). Volkmar and McPartland (2014) argued that the PDD-NOS subtype had been the least studied sub-category of autism; nevertheless, its inclusion in the DSM had important implications for research as it contributed to the emergence of the concept of the broader autism prototype (BAP; Piven et al., 1997; Piven & Palmer, 1999). Third, a discovery about Rett syndrome being a single-gene disorder as caused by loss-of-function mutations in the gene Methyl-CpG-binding protein 2 (MECP2) on the X chromosome (Zoghbi, 2016) made it clear that revisions of the existing classification of autism and pervasive developmental disorders were necessary (Volkmar & McPartland, 2014).

The work on revisions of the obsolete versions of both diagnostic classifications began in 1999 for DSM (Blashfield Keeley, Flanagan, & Miles, 2014; Clark et al., 2017) and in 2007 for ICD (World Health Assembly [WHA] 72.29, WHO, 2019), respectively. The final, fifth edition of DSM
was released in 2013 (Blashfield et al., 2014), while the pre-final version of the ICD-11 was released in 2018 (Reed et al., 2019) followed by the agreement among 194 member countries to adopt the new ICD version a year later, in May 2019 (WHO, 2019). The revision process of both classification taxonomies occurred in close collaboration between their developers to achieve the harmonization of definitional and conceptual differences for a number of mental, behavioural and developmental disorders that existed in previous versions of ICD and DSM (First, 2009). Regarding autism, key similarities in definition of the disorder in two classifications include the conceptualization of autism as a spectrum that replaced the notion of pervasive developmental disorders (Lord & Jones, 2012) as well as change in domain criteria from triad to dyad of impairments, i.e. from (1) social; (2) communication; (3) stereotyped and repetitive behaviors and interests to (1) social communication and (2) stereotyped and repetitive behaviors and interests (Jackson & Volkmar, 2019). Another similarity is the removal of both Child Disintegrative Disorder and Rett syndrome as autism subtypes.

On the other hand, there are a number of important differences between two diagnostic systems. Firstly, the subthreshold category of PDD-NOS was eliminated from DSM (Volkmar & Reichow, 2013). Secondly, in the DSM-5 the subtype Asperger’s disorder was subsumed under the umbrella term of ASD to address the confusion concerning diagnostic distinctions between Asperger’s disorder and high-functioning autism (Lord, & Jones, 2012; de Giambattista et al., 2019). To address a predictable concern that individuals with the DSM-IV diagnoses of Asperger’s disorder and PDD-NOS might lose eligibility to services under the new diagnostic term ASD, the DSM-5 developers introduced a new diagnostic label – Social Communication Disorder – to define a condition in those children who would show impairments in the social communication domain without presence of stereotypical behaviors (Clark et al., 2017; Jackson & Volkmar, 2019). These decisions were met with resistance by individuals diagnosed with Asperger’s disorder, parents and some clinical researchers (Jackson & Volkmar, 2019). Major concerns expressed by advocacy organizations were a possible loss of identity gained through the diagnostic label of Asperger’s disorder, and a fear of increased stigma due to sharing the same diagnostic label of autism with people who had more severe cognitive and behavioral impairments (Hansen, McDougle, & Volkmar, 2013 as cited in Jackson & Volkmar, 2019). An additional feature of the DSM-5 was the introduction of specifiers indicating co-existing intellectual and language impairments and severity levels were introduced (APA, 2013).

Unlike the DSM-5, the ICD-11 included several autism subtypes by retaining subcategories of childhood autism and Asperger syndrome from the ICD-10 under the umbrella term of ASD (Reed et al., 2019). More specifically, “Asperger syndrome” appears in the ICD-11 as a narrower term for an ASD subtype defined as *Autism spectrum disorder without disorder of*
<table>
<thead>
<tr>
<th>DSM definitions of autism and subtypes</th>
<th>ICD definitions of autism and subtypes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DSM-II (1968)</strong></td>
<td>Schizophrenia</td>
</tr>
<tr>
<td></td>
<td>Childhood type</td>
</tr>
<tr>
<td><strong>DSM-III (1980)</strong></td>
<td>Pervasive developmental disorder</td>
</tr>
<tr>
<td></td>
<td>Infantile autism</td>
</tr>
<tr>
<td></td>
<td>Childhood onset pervasive developmental disorders</td>
</tr>
<tr>
<td><strong>DSM-III-R (1987)</strong></td>
<td>Pervasive developmental disorder</td>
</tr>
<tr>
<td></td>
<td>Autistic disorder</td>
</tr>
<tr>
<td></td>
<td>Pervasive developmental disorder-not-specified</td>
</tr>
<tr>
<td></td>
<td>Autistic disorder</td>
</tr>
<tr>
<td></td>
<td>Asperger’s disorder</td>
</tr>
<tr>
<td></td>
<td>Pervasive developmental disorder-not-specified</td>
</tr>
<tr>
<td></td>
<td>Childhood disintegrative disorder</td>
</tr>
<tr>
<td></td>
<td>Rett’s disorder</td>
</tr>
<tr>
<td><strong>DSM-5 (2013)</strong></td>
<td>Autism spectrum disorder</td>
</tr>
</tbody>
</table>

Table 1. DSM’s and ICD’s definitions of autism and its subtypes over time. Adapted from Osley and Cermak (2014).
intellectual development and with mild or no impairment of functional language (WHO, 2019). In addition, a separate subtype – autism spectrum disorder, unspecified – is also listed (WHO, 2019). As it has been noted earlier, the pre-final version of the ICD-11 was released in 2018. Clark et al. (2017) noted that the ICD-11 developers had an advantage to learn from the proposed and final versions of the diagnostic criteria in the DSM-5. However, the authors pointed out that both classification systems somewhat differ in their goals. As an international diagnostic tool, the ICD-11 aims to ensure its global applicability; and therefore its diagnostic criteria have been written in a more flexible and simplified language to be able to use in other cultural contexts and to facilitate diagnostic process (Saxena, 2019). On the other hand, in contrast to the DSM-5, the ICD-11 did not include sensory issues of ASD, such as over- or under-sensitivity to sounds and touch, although they had been initially described by Kanner (Simmons, 2019).

In summary, the changes in the clinical descriptions, definitions and conceptualization of autism over time can be viewed as dynamic and constantly evolving (Table 1). However, this dynamics should be considered within a broader context of conceptualization of mental disorders as well as through various approaches to viewing psychopathology as reflected in each edition of DSM or ICD diagnostic systems.

Controversies with diagnostic classifications for mental disorders
Although both existing classification taxonomies – the DSM and the ICD – described in the literature as ‘gold standard’ (Fusar-Poli et al., 2019) have been useful in categorizing mental disorders, in general, and in describing ASD, in particular, they have received criticism over its limitations. For instance, some authors (e.g. Canino & Alegría, 2008) noted that classifications and operational definitions of mental disorders have not been consistent over time with large variations between and within both systems. Canino and Alegría (2008) argued that one of the reasons for this is the lack of biological markers for mental disorders. Indeed, as Clark et al. (2017) wrote, “… our major classification systems are based almost exclusively on observable behaviors (signs) and self-reported feelings and thoughts (symptoms)…” (p. 73). As a result, conceptualization of mental disorders using existing classification taxonomies presents a difficult task.

Another reason contributing to difficulties in conceptualization of mental and neurodevelopmental disorders is a lack of common agreement on the definition of mental disorders, which has been marked by ongoing debates among cognitive psychologists, historians, philosophers, and social anthropologists (Blashfield et al., 2014; Clark et al., 2017). For instance, Wakefield (2007) in his critique of both DSM and ICD taxonomies emphasized the importance of considering contextual factors in diagnosing mental illness. Following his argument, Wakefield proposed a harmful dysfunction defini-
tion of mental disorder, where the term “harm” refers to the value-based component of negatively perceived mental conditions in a given socio-cultural context, while the term “dysfunction” refers to the value-free scientifically factual component of mental conditions based on an evolutionary theory to view mental functioning as a natural phenomenon. Some authors criticized Wakefield’s view of the nature of mental disorders for being “essentialist” (Blashfield et al., 2014, p. 36) or lacking clinical utility in making diagnostic assessments (see Clark et al., 2017). In sum, these discussions point to an important limitation of the DSM and the ICD systems—a difficulty to provide meaningful explanations of what operational definitions of mental disorders could mean within certain cultural contexts (Canino & Alegría, 2008). Both classification systems are essentially Western medical notions stemming from European thinking (Blashfield et al., 2014; Fusar-Poli et al., 2019; Kendler, 2009; Kleinmann, 1995), resembling as such the existing classifications of animal species or Carl Linnaeus’s classification of plants, although the DSM and ICD classifications do not categorize human beings with disorders “but rather the disorders that people may develop” (Clark et al., 2017, p. 93)

On a global level, there is a lack of agreement on what the concept of mental disorder actually means, as various laws across different countries use different terms (without defining them) to denote mental disorders, e.g., ‘mental disturbance’, ‘lunacy’, ‘insanity’ (van Dorn, 2016, p. 1108), thus adding to the complexity of the situation. As a result, in many developing, non-Western countries, the field of child psychiatry is only in its infancy, and mental health care or special educational services are not well established (see Bello-Mojeed, Bakare, & Munir, 2014; Hussein & Taha, 2013; Imran & Azeem, 2014; Shrestha & Santangelo, 2014). In regard to ASD, these authors note that in many low- and middle-income countries attention to autism in children is not given a high priority, thus leaving many children with ASD and other developmental disabilities undiagnosed and without treatment. Research has also revealed that that general public in some non-Western countries had very low awareness about autism (Abubakar, Ssewanyana, de Vries, & Newton, 2016; Habib, Prendeville, Abdussabur, & Kinsella, 2017). For instance, several studies conducted with parents of children with ASD from diverse cultural backgrounds have shown that the word “autism” was unknown in their cultures (Andersson, 2007; Fox et al., 2017; Hussein, Pellicano, & Crane, 2018; Ilias et al., 2017; Shrestha & Santangelo, 2014). For instance, a study conducted with Somali parents to children with ASD in the United Kingdom (Fox et al., 2017), reported that the word “autism” did not exist in the Somali language. Indeed, the term “autism” can be considered as an inherently Western concept. Although the term “autism” had been introduced into the international classification such as the ICD several decades ago, in a number of developing countries the notion of autism still remains “a mystery” for many parents of children with ASD (Sa-
madi & McConkey, 2011, p. 5); moreover, it is still unknown for many medical or healthcare practitioners (Imran & Azeem, 2014; Shrestha & Santangelo, 2014).

Several authors (e.g., Clark et al., 2017; Stein, 2014) argue that research evidence that accumulated over the past decades, have shown that mental and neurodevelopmental disorders do not have a single origin, indicating that aetiology of mental disorders is multifactorial, i.e. presents a function of a complex interplay of diverse causal factors (genetic, biological, psychological, social, and cultural). Clark and colleagues (2017) discuss the issue of multicausality in relation to the classification systems as follows:

... [I]t is important to raise the issue of multicausality because of continuing concerns that biological causes and treatments for mental disorders receive disproportionate attention and resources, whereas psychological, social, and cultural factors are relatively unaddressed, despite compelling evidence for their importance. Therefore, the multicausality issue in relation to mental-disorder classification might be reframed as being about the ways in which these classifications offer systematic opportunities to note and record the influences of psycho-socio-cultural factors, thereby providing a basis for more research into them and for the development of additional assessment and intervention strategies. (p.100).

Nevertheless, despite the widespread awareness about multicausality of mental disorders, current understanding of underlying causal mechanisms behind mental, behavioral and neurodevelopmental disorders is still rather basic (Amaral et al., 2019; Clark et al., 2017). Thapar et al. (2017) argue that multifactorial aetiology is one of the reasons for why conceptualization of neurodevelopmental disorders (including ASD) is currently problematic.

Another problematic issue is the notion of thresholds used by the classification systems (Clark et al., 2017). A threshold refers to a line (i.e. a border) that clearly separates normality from disorder, and is reflected in strict (or even rigid) diagnostic criteria set by the classification systems. Setting thresholds for mental disorders has several important unintentional consequences. For instance, in the case of the DSM system, highly specified thresholds for mental disorders can lead to reification of mental disorders – a strong belief among professionals, general public and media that the way these disorders are defined and described are non-arbitrary (i.e. true) and, therefore, represent “real”, or natural phenomena, despite lack of firm empirical evidence for distinctions among categories of some mental disorders (Clark et al., 2017, p. 118). This belief can also mislead general public in a sense that these “real” mental disorders would be exactly the same in all cultures around the world, which could be a false assumption. As Clark and her colleagues pointed out, much research using the DSM criteria had been mainly conducted in English-speaking countries or Western Europe, i.e. high-income countries, although 80% of global population live in low-and
middle-income countries (Reed et al., 2019), including 95% children with developmental disabilities below the age of 5 years (de Vries as cited in Amaral et al., 2019). Regarding the ICD system, although it is based on the Western biomedical approach to mental health problems (WHO, 2019), the latest WHO revision of the classification strove to achieve a greater clinical utility and applicability across the world’s various geographical regions, countries, and practitioners in different disciplines (Reed, 2010; Reed et al., 2019). One such example in relation to autism could be the ICD-11’s broader diagnostic criteria for ASD where the notion of symbolic play does not appear as it is the case with the DSM-5.

Another consequence related to the issue of threshold is social stigma that is attached to mental disorders. For this reason, Clark et al. (2017) urge not to consider the diagnostic thresholds as “non-arbitrary” (i.e. real or true), but as “semi-arbitrary” in order to raise public awareness about mental disorders and “help reduce the stigma that follows upon the false belief that there is a clear line between those with mental disorders and “the rest of us” (p. 118). For instance, as it has been described earlier, the decision to subsume the subtype of Asperger’s disorder in the DSM-5 under the ASD term met strong opposition from both individuals diagnosed with Asperger’s disorder and advocate organizations, partly due to fear of stigma associated with autism (Jackson & Volkmar, 2019). The newly revised ICD version – the ICD-11 – will probably escape this reaction as it includes Asperger syndrome as a separate subtype (see ICD-11, WHO, 2019). In addition, historical changes in clinical definitions and conceptualizations of ASD have contributed to an issue of non-replication of ASD research findings (Webb, cited in Amaral et al., 2019).

To address some of the controversies and challenges with diagnostic classification systems, recently there have been several important developments in the field. These include (1) the Research Domain Criteria (RDoC) initiative (Insel, 2010), (2) the introduction of the Cultural Formulation Interview (CFI) into the DSM-5 (APA, 2013), (3) the inclusion of new supplementary chapters/sections in the ICD-11 – Chapter 27 on traditional medicine to collect data on the use of complementary and alternative medicine (CAM) and a section on functional assessment before and after treatment, thus highlighting the joint use of the ICF – the ICD’s sibling (Clark et al., 2017). The ICD-11 also contains Chapter 24 on Factors influencing health status that is directly aligns with environmental factors in ICF. Thus, the ICD-11 recognizes the influence of external factors on people’s health (ICD-11, Lancet, 2019). In the field of autism, the ICF Core Sets for ASD have been developed (Bölte et al., 2019). A brief description of the RDoC, the CFI, and the ICF Core Sets for ASD and their implications for autism are presented below.
Research Domain Criteria (RDoC)

In 2009, the U.S. National Institute of Mental Health (NIMH) initiated the Research Domain Criteria (RDoC) project that applies a neuroscience-based approach to psychiatric classification (Insel, 2010). The RDoC framework was initiated first and foremost for research purposes; it conceptualizes mental illnesses as “disorders of brain circuits” (Insel, 2010, p. 749) and does not provide definitions to any specific disorders (Clark et al., 2017). According to Insel (2010), dysfunction in brain circuits can be identified by using methods applied in genetics and clinical neuroscience (e.g. functional neuroimaging and electrophysiology), which would point to specific biomarkers underlying clinical presentation of illness. Compared to DSM and ICD – traditional, “gold standard” classifications of mental disorders that are based on symptom-based, categorical diagnoses (Fusar-Poli et al., 2019) – the RDoC approach focuses primarily on causal factors (Clark et al., 2017). Fusar-Poli et al. (2019) argue that the RDoC paradigm addresses the issue of comorbidity and heterogeneity.

However, the RDoC framework received a wide criticism from leading experts in the field (Kirmayer, Lemelson & Cummings, 2015) for lack of clinical utility (Jablensky & Waters, 2014), for not considering contextual factors (Sartorius, 2014; Wakefield, 2014) or for not taking a developmental perspective (Sartorius, 2014), among others. Insel (2014) addressed some of these criticisms by noting that the proposed RDoC’ domains and levels of analysis present a point of departure in the effort to organize research to understand psychopathology. Indeed, as Clark et al. (2017) argue that at present the RDoC framework is denoted as “Version 1.0”, implying that the novel approach will inevitably change as new research evidence accumulates (p. 96). Moreover, arguing in favour of the RDoC as a multidisciplinary, integrative approach to study mental disorders, the authors note that intellectually, the RDoC developers were inspired by research work of developmental psychopathologists – system theorists. By having applied concepts drawn from the general system theory (von Bertalanffy, 1968 as cited in Capra, 1996), those researchers suggested viewing psychopathology as a result of complex interactions between an individual as an open system and his/her environment (Clark et al., 2017). It is important to note that the research project described in the present dissertation has also been inspired by the system perspective on child development and early childhood intervention (see Björck-Åkesson & Granlund, 2004; Wachs, 2000).

When applied to neurodevelopmental disorders, such as ASD or ADHD, several authors noted that all three frameworks – DSM, ICD, and RDoC – should be viewed as complementary (Doernberg & Hollander, 2016; Levy, 2014), although researchers in the field of ASD are particularly hopeful that the RDoC’s dimensional, cross-diagnostic approach might help untangle the complexity of relationships underlying comorbidity and heterogeneity of ASD (see Amaral et al., 2019).
Cultural Formulation Interview in DSM-5

The revised, fifth edition of the DSM (APA, 2013) introduced an approach to cultural assessment, the Cultural Formulation Interview (CFI), thus expanding the Outline for Cultural Formulation (OCF) included in the previous edition of the Manual, the DSM-IV. The CFI is described as an evidence-based tool composed of three types of semi-structured interviews to assist clinicians in making person-centered cultural assessments to inform diagnosis and treatment planning (Lewis-Fernández, Aggarwal & Kirmayer, 2016). These are the core interview protocol of 16 open-ended questions; the ICF-Informant version to obtain information from caregivers, relatives, or friends (in case if the individual is, e.g. a young child), and 12 supplementary modules to obtain more information to complement basic assessment (Lewis-Fernández et al., 2016). By aiming to improve outcomes of mental health care for an individual and eliminating health disparities, the CFI systematically assesses the following categories: cultural identity of the individual (description of the individual’s racial, ethnic, or cultural reference group; language abilities and preferences, as well as religious affiliation, socioeconomic background, place of birth, migrant status, and sexual orientation); cultural conceptualization of distress (description of the cultural constructs that influence the way the individual experiences, understands, and communicates his or her problems to others); psychosocial stressors and cultural features of vulnerability and resilience (identification of stressors and supports in the individual’s social environment; the role of religion, family, neighbors, friends, co-workers in providing support); cultural features of the relationship between the individual and the clinician (identification of differences in culture, language, and social status between the individual and the clinician that may influence diagnosis and treatment), and overall cultural assessment (summary of the implications of the cultural formulation) (APA, 2013). As it has been noted earlier, the CFI is based on the conceptual framework of explanatory models of illness or disability put forward by Arthur Kleinman (Kleinman et al., 1978; Kleinman, 1980).

Some researchers have published their findings from the use of the CFI with children suspected for ASD in clinical practice. For instance, La Roche et al. (2018) described how a clinician developed a family-centered intervention plan based on information gained from the CFI assessment for an 8-year old Latino boy: involving the child’s grandmother and incorporating pictures from his favourite cartoon into the ABA treatment protocols. In other clinical case studies with young children, although not suspected for ASD, the use of the CFI Informant version has also been proven useful, although the researchers suggested a new, supplementary module for young children be developed (La Roche & Bloom, 2018).
Environmental factors in ICF and ICF Core Set for ASD
The International Classification of Functioning, Disability and Health (ICF) has been proposed to be a common language between different professional groups including teachers, and classifies various environmental factors, including cultural dimension (WHO, 2001). The most recent research initiative on application of the ICF(-CY)’s framework to develop standardized ICF Core Sets for ASD for describing functioning in individuals with autism across different cultures (Bölte et al., 2014; Bölte et al., 2019) could be a move forward to understand the impact of cultural factors on assessment and interventions planning. However, despite these advances in addressing the role of various environmental influences on child’s functioning in various settings, the Environmental section of the ICF’s general framework, and of the ICF Core Sets for ASD, lacks specificity in describing certain environmental factors, for example, on the level of family, which can in turn affect interventions planning (Bölte et al., 2019; Klang, 2012; Mahdi, 2019; Zakirova Engstrand & Granlund, 2009). Previous studies have provided suggestions to include additional coding schemes to achieve a more fine-grained descriptions of environmental factors in the ICF framework. For instance, based on the findings of the interview study with parents of children with disabilities in the cultural context of Kyrgyzstan, Central Asia, Zakirova Engstrand and Granlund (2009) suggested adding more codes to categories ‘Immediate family’ and ‘Extended family’ contained in Chapters 3 and 4 (‘Support and relationships’, and ‘Attitudes’, respectively). More specifically, they recommended inclusion of separate codes for child’s both parents, for siblings, as well as for grandparents and other child’s relatives. The researchers especially emphasized the need for separate coding of attitudes of maternal and paternal grandparents to address a possibility of differential nature of relationships between child’s parents and paternal or maternal grandparents, which could present either protective or risk factors for child’s functioning and health in the context of family.

Nevertheless, if developed further, application of the ICF Core Sets for ASD could inform professionals, including special and general teachers, about what impact certain environmental factors could have on functioning of children with ASD which, in its turn, could help them accommodate educational practices to meet the unique needs of these children in classroom or other settings.
ASD in the cultural context of Sweden

In recent years Sweden, a country located in Northern Europe, is increasingly becoming a multi-national and culturally diverse society. Migration is one of the main factors that contribute to cultural diversity of the previously homogenous nations (Bäärnhjelm et al., 2013). Data from National Agency for Education ([NAE], 2016) showed that during the 2014-15 academic year almost 225 500 students (24% of all students enrolled into compulsory school) were registered as entitled to mother tongue tuition and/or Swedish as a second language. Students speaking Arabic, Somali and Albanian represented more than 60% of all students who participated in mother tongue tuition that year (NAE, 2016).

Recent estimates of prevalence rates of ASD in Sweden for ages 0-17 years olds is 1.44%, and for 18-27 years olds – 1.76% (Idring et al., 2015). Parental migration status has been reported as being one of the contributing risk factors of developing autism in children (Haglund & Källén, 2011). Later studies that examined risks factors for ASD in young children have also studied associations with ethnic origin of research participants. For instance, in a total population-based study Idring et al. (2014) investigated relationships between parental age and risk for ASD in children. Using maternal region of origin to describe ethnic background of children with ASD (n=4746), the investigators found that 9.3% of mothers had been born in Europe outside Sweden while 15.9% of mothers had been born outside Europe. Cederlund, Miniscalco and Gillberg (2014) noted high percentage of children with ASD, who had both parents born outside Sweden (61%). However, underlying mechanisms of associations between ethnic origin, migration status and ASD are still unclear, and more research is required to understand this phenomenon (Idring et al. 2015). Although Swedish researchers do consider ethnicity factor in ASD prevalence studies (Zaroff & Uhm, 2012), there is little evidence on what impact this contextual variable can have on intervention effectiveness for individuals with ASD. A better understanding of how ethnic and cultural factors are described in ASD research literature therefore is needed.

Formal support system

Young children diagnosed with ASD and their families are entitled to publicly financed support services under several national legislative acts that fall under the jurisdiction of municipalities and regional county councils. While provision of healthcare falls under jurisdiction of regional county councils, provision of educational, social and transportation services falls under jurisdiction of municipalities. Thus, provision of services to preschool-aged children with ASD can be described as dual (Roll-Pettersson, Olsson, & Ala i-Rosales, 2016). For instance, while municipalities take responsibility for preschool placement and personal assistance (or other services) based
on demonstrated needs (Zakirova Engstrand & Roll-Pettersson, 2014), county councils are in charge of provision of healthcare services through Child habilitation centers – special units accountable for disability services delivery (Långh, Cauvet, Hammar, & Bölte, 2017). Disability services for young children with autism include provision of the EIBI, speech therapy, physio- and occupational therapy. EIBI is usually carried out at community settings by preschool teachers under supervision of professionals from child habilitation centres. Professionals at child habilitation centres also regularly hold group-based, psychoeducational training sessions for child’s immediate family members (parents and child’s siblings), extended family members (e.g. grandparents), and preschool staff (Barnevik Olsson, 2016).

All services to children with ASD and their families are provided free of charge regardless of their socio-economic status, ethnic/cultural background, immigration status (e.g. asylum seekers), place of residence (urban or rural), or service provider (public or private). An important law that specifically regulates services and support provided to children diagnosed with ASD their families is the Act Concerning Support and Service for Persons with Certain Functional Impairments (1993:387; known as LSS, in Swedish). Young children with ASD are entitled to eight services according to this law: (1) counselling and other personal support; (2) personal assistance; (3) companion service; (4) personal contact; (5) relief service in the home; (6) short-term stay away from home; (7) short period of supervision for schoolchildren over the age of 12, and (8) living arrangements in a family home or in a residence with special services.

Another important legislation is the Education Act (2010:800) that regulates provision of educational services to all children in Sweden. Young children with special needs or disabilities, including children with ASD, usually attend regular (i.e. inclusive) preschools (Lundquist, Allodi Westling, & Siljehag, 2015). The National Curriculum for Preschool (Lpfö 1998/2016) that regulates preschool activities underscores the importance of meeting unique needs of children with special educational needs/disabilities to achieve positive developmental outcomes. However, young children with special needs/disabilities are not always given equal opportunities for active participation in classroom activities (Swedish Schools Inspectorate, 2017). In relation to children with ASD, low levels of ASD knowledge among preschool teachers working in inclusive classroom settings is a significant barrier to provision of quality services (Zakirova Engstrand & Roll-Pettersson, 2014). Other described barriers were lack of knowledge and allegiance towards EIBI (Långh et al., 2017), and lack of collaboration between various agencies responsible for provision of services for children with ASD and their families (Westman Andersson et al., 2017).
Research priorities

Family environment is a key factor in successful intervention for children with ASD (Hastings, 2008) and, therefore, research focusing on family perspectives investigating families’ needs, values, goals and beliefs in relation to their children with ASD is necessary. Both internationally and in Sweden, there is limited research available concerning how families with diverse ethnic, cultural and linguistic backgrounds perceive their child’s autism and how they organize everyday activities to achieve well-being in the context of the cultural learning environment of their communities. The few studies that do exist in this area within the Swedish context, examined perspectives of professionals working with children with ASD and their families. Therefore, these studies provide only some insight into how parents to children with ASD from diverse ethnic, cultural and linguistic backgrounds perceive their child’s disability, access to information about ASD and availability of services, and their collaboration with preschool- and school staff as well as with habilitation specialists.

Concerning research on extended family members, such as grandparents, the majority of existing studies that examined perspectives and experiences of grandparents of grandchildren with autism were conducted outside Sweden, mainly in English-speaking countries. In Sweden research on grandparents of children with ASD is virtually non-existent, which points to a pressing need to initiate research in this area. The current research project intends to address this gap in the literature and contribute to the field.

Furthermore, it would be advantageous to explore methodological practices of Sweden-based ASD researchers in reporting cultural factors in their scientific publications as previous studies showed that clear reporting of cultural characteristics of research participants enhances methodological rigor of research (Kistner & Robbins, 1986; Pierce et al., 2014) and also facilitates developing and provision of culturally sensitive, individualized interventions and services, tailored to meet unique needs of each individual child with ASD and his/her family members (Stahmer et al., 2011; West et al., 2016). Given the fact that Sweden is a multicultural society, this presents an important and timely research task.
Methods

Mixed Methods Design
To address the aims of the research project and answer its research questions, a mixed method research methodology was used. Mixed methods research has been defined as “the process of using quantitative and qualitative methods in order to provide multiple ways of making sense of the social world” (Greene, 2007, p.20). As part of the definition of mixed methods research, Klassen et al. (2012) provide the following guidelines for conducting studies using this approach:

(1) focusing on research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences, (2) employing rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs, (3) utilizing multiple methods (e.g., intervention trials and in-depth interviews), and (4) intentionally integrating or combining these methods to draw on the strengths of each. (p. 378).

Additionally, mixed methods studies provide opportunities for the integration of a variety of theoretical frameworks and use diverse philosophical positions through “a dialectical discovery” (Crewell, Klassen, Plano Klark, & Clegg Smith, 2011, p. 4).

Philosophical Framework
In the present thesis, the research project was conducted within the pragmatic paradigm as the philosophical framework guiding mixed methods research (Teddle & Tashakkori, 2012). As Miles and Huberman (1994) note the actual practice of empirical research in studying complex social environments require the use of multiple research methods, where the boundaries between polarized epistemologies become indistinct. The authors called for a more pragmatic, “ecumenical” epistemology to generate knowledge (p. 5). Similarly, Morgan (2007) argues that a key aspect in the pragmatic approach to
knowledge is to achieve a shared understanding of a phenomenon and take a “joint action” through engaging into meaningful intellectual communication across epistemological boundaries (p. 67). Morgan (2007) describes the strengths of the pragmatic approach in the following way:

The great strength of this pragmatic approach to social science research methodology is its emphasis on the connection between epistemological concerns about the nature of the knowledge that we produce and technical concerns about the methods that we use to generate that knowledge. This moves beyond technical questions about mixing or combining methods and puts us in a position to argue for a properly integrated methodology for the social sciences. (p. 73).

Furthermore, as Maul and Singer (2009) pointed out, within the pragmatic paradigm, “research in the field of disability is thought to be the most valuable when it emphasizes the discovery of effective approaches to assessment and intervention for people with disabilities” (p. 157).

Rationale for using mixed methods design

There are several reasons for why the present research project employed the mixed methods methodology to answer its research questions. First, a mixture of quantitative and qualitative methods allows exploring complex issues affecting family settings and processes, e.g., the dynamic and interdependent nature of relationships within family; the role of contextual factors on relationships; changes across time, and “the role of meanings, interpretation, and beliefs in social interactions” (Weisner & Fiese, 2011, p. 2011). Second, integration of both qualitative and quantitative methods facilitates a more comprehensive assessment of cultural variations in family organisations, family goals, beliefs and practices (van de Vijver et al., 2010; Weisner & Fiese, 2011). This in turn, permits a deeper and more nuanced understanding of the role of contextual influences (on family- and societal levels) on child’s a/typical development, thus, having direct implications for development of family-centred intervention research and practice (Yoshikawa & Hsueh, 2001; Yoshikawa, Weisner, Kalil, & Way, 2008). Third, integration of various methodological approaches is preferential when studying complex issues in research on health disparities through the lens of systemic thinking (Diez Roux, 2012). In addition, methodologically mixed methods are seen as useful to enhance the quality of research and increase the validity of findings (Miles & Huberman, 1984; van de Vijver et al., 2010).

Convergent parallel design

Mixed methods research methodology identifies several types of designs: (1) convergent (parallel or concurrent) designs; (2) sequential (explanatory and exploratory) designs; (3) embedded (or nested) designs, and (4) multiphase designs (Creswell et al., 2011). In the present dissertation, the convergent
**parallel mixed methods design** was used (see Figure 3). In this type of design, the quantitative and the qualitative data are collected simultaneously, followed by an integrated analysis of the results (Creswell, 2014; Guetterman, Fetters, & Creswell, 2015). In this project, the results of quantitative and qualitative analyses will be presented separately in the Results section of the thesis, while data integration at the levels of analysis and interpretation will be presented in the Discussion section.

![Diagram of data comparison and integration](image)

*Figure 3. Convergent parallel design as a framework for organizing research methods. Adapted from: DeCuir-Gunby & Schutz (2017).*

**The role of the researcher**

The qualitative component of the research project involved reflexivity. Reflexivity refers to the process when the researcher evaluate his or her own background, beliefs, perceptions and biases on the qualitative research process (Creswell & Miller, 2000; Krefting, 1991). The researcher (RZE) originally comes from Kyrgyzstan – a multicultural society located in Central Asia. Kyrgyzstan used to be a part of the former Soviet Union – a country that does not exist any longer. The researcher belongs to one of the national minority groups that speaks one of the Turkic languages; however, she identifies her first language as Russian, although she has been fluent in local Turkic languages. Educational aspirations allowed her mastering both English and Swedish. These are the examples of how the researcher’s cultural identity has changed over time. The researcher believes that her cultural, educational, and professional background (trained as a medical nurse first, and later as a teacher and special educator) have allowed her to develop sensitivity to issues related to cross-cultural research with families that have children with disabilities. For instance, she has an experience of conducting an interview study with Uzbek and Kyrgyz families with various types of disabilities in Kyrgyzstan (Zakirova Engstrand & Granlund, 2009). In addition, she worked as a special educator with children with ASD and other neurodevelopmental disabilities in two regular schools in Sweden. Thus, it is...
possible that the researcher’s immigrant background could facilitate recruitment of culturally diverse families into research. In addition, it is possible that the researcher’s professional affiliation as the special educator to some extent could affect parents’ participation in the study in the way that parents wanted to hear or learn more about autism or available special educational support or intervention. Indeed, some parents did make some inquiries during interviews. At the same time, during the research process, the researcher realized that many parents had already acquired extensive knowledge about ASD and services available to their children, and therefore, learning experience was mutual both for the researcher and the study participants.

Sample/Participants

Study 1
Thirty (n=30) peer-reviewed articles published in English in academic journals between 2013 and 2015 were identified and included for a review. All included studies were conducted by Sweden-based scholars in the field of ASD research.

Characteristics of included studies
According to the criteria/typology of research areas provided by Milner and Cho (2014), the reviewed articles were categorized as follows: eighteen studies (n=18, 60%) as basic (i.e. bio-medical studies, risk factors); six studies (n=6, 20%) as descriptive (diagnosis and prevalence studies), three studies (n=3, 10%) as treatment/intervention, and three (n = 3, 10%) as other (e.g. quality of life etc.).

Study 2
Participants were parents of preschool-aged children diagnosed with ASD from diverse cultural, ethnic and linguistic backgrounds (including Swedish). Table 3 presents children’s characteristics.

Parents characteristics
Parents age ranged from 31 to 55 years, and a majority had a graduate degree at tertiary educational level (n=10) with 3 of them holding master degrees; 5 parents completed upper-high school, and 2 had junior high school as highest educational level. In terms of parents’ employment status, at the time of data collection 5 parents were employed part-time and 3 – full-time; one parent had a paid internship, while another parent was waiting for internship; 3 were unemployed, one was on her parental leave, 2 parents were students,
and 1 parent described herself as a housewife. Parents’ religious beliefs included Islam (n=9), Christianity (n=3), Judaism (n=1), with 4 parents described themselves as ‘non-religious’. The average monthly family income by the time of data collection ranged from less than 14,000 SEK (≈1474 Euro) to more than 45,000 SEK (≈4737 Euro).

Table 3. Child characteristics in Study 2.

<table>
<thead>
<tr>
<th>Child Characteristics (n = 16)</th>
<th>Mean (SD)</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child age (in years)</td>
<td>5.7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Range: 3 – 6.11</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Girls</td>
<td>4 (25)</td>
<td></td>
</tr>
<tr>
<td>- Boys</td>
<td>12 (75)</td>
<td></td>
</tr>
<tr>
<td>Child’s age at first symptoms onset (in months)</td>
<td>18.81 (9.68)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Range: 6 – 36</td>
<td></td>
</tr>
<tr>
<td>Child’s age at diagnosis (in months)</td>
<td>37.06 (13.89)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Range: 14 – 72</td>
<td></td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Intellectual disability (ID)</td>
<td>8 (50)</td>
<td></td>
</tr>
<tr>
<td>- Social disorder</td>
<td>1(6.3)</td>
<td></td>
</tr>
<tr>
<td>Child’s level of language</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Non-verbal</td>
<td>5 (31)</td>
<td></td>
</tr>
<tr>
<td>- Minimally verbal (some words or phrases)</td>
<td>4 (25)</td>
<td></td>
</tr>
</tbody>
</table>

Study 3

Participants were grandparents of preschool-aged children with ASD who were enrolled into publically funded disability intervention programmes at the Autism Center for Small Children (ACSC) at Habilitation & Health in Stockholm (Stockholm County Council publicly funded disability services).

Grandparents characteristics

All participants (n=120) were traditional (i.e. non-custodial) grandparents; of them maternal grandmothers were 30.5% (n=36); maternal grandfathers – 17.8% (n=21); paternal grandmothers – 29.7% (n=35), and paternal grandfathers – 15.3% (n=18). Six grandparents (5%) described themselves as step-grandparents; two participants (1.7%) did not specify their relationship to the grandchild. None reported being foster grandparents. Of the total 120 participants 63.3% (n=75) were women, and 36.4% (n=43) were men. The overwhelming majority of the participants were Swedish-speaking (90.1%); six participants (5.4%) spoke other European languages, while five (4.5%) iden-
tified their first language as spoken outside the European region. The majority of grandparents reported their being retired (n=72, 60.5%), and more than a half had a graduate university degree (n=65, 55.6%). Seventy grandparents (n=70, 62.5%) reported living in a large city. Almost 85% of the respondents reported their health condition as “good”. Table 4 provides information on grandchildren’s characteristics as reported by study participants.

Table 4. Child characteristics in Study 3.

<table>
<thead>
<tr>
<th>Child Characteristics (n = 129)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child age (in years, missing n = 1)</td>
</tr>
<tr>
<td>Gender (missing n = 5)</td>
</tr>
<tr>
<td>- Girls</td>
</tr>
<tr>
<td>- Boys</td>
</tr>
<tr>
<td>Difficulties (as perceived by grandparents)*</td>
</tr>
<tr>
<td>(missing n = 18)</td>
</tr>
<tr>
<td>- No difficulties</td>
</tr>
<tr>
<td>- Yes, minor difficulties</td>
</tr>
<tr>
<td>- Yes, definite difficulties</td>
</tr>
<tr>
<td>- Yes, severe difficulties</td>
</tr>
</tbody>
</table>

*As reported by their grandparents on the Impact Supplement scale items of the SDQ-Swe.

Instrumentation

Measures and instruments used to collect and analyse data in the included studies are described below in an alphabetical order.

Demographic survey

The demographic survey is a modified and translated version of the demographic section of the Needs Survey for grandparents of children with disabilities developed by Dougherty (2009). It consists of 11 questions and asks participants to indicate their gender, age, mother tongue (as proxy for ethnicity), level of education, employment, perceived health, urban or rural setting of grandparent residence, and geographic proximity of grandparent residence to grandchild with ASD. The survey also asks questions on grandchild’s age and gender. The instrument was used in study 3.
Semi-structured in-depth interview

The semi-structured in-depth interview is based on the Ecocultural Family Interview (EFI) designed to assess sustainability of family’s daily routine and activities in response to having a child with a disability (Weisner et al., 1997). The interview has a qualitative format using open-ended questions and is based on ethnographic interview traditions (Weisner et al., 1997). The interview usually begins with an orienting question: “Walk me through your day. From the time you get up to the time you go to bed, what are your activities throughout the day? What does it take to make those activities happen?” (Weisner, 2010, p.218). The EFI has been used with families of children with various types of disabilities in various cultural settings, including Sweden (Daley, Weisner, & Singhal, 2014; Mas, Giné, & McWilliam, 2016; McConnell & Savage, 2017; Wilder & Granlund, 2014; Zakirova Engstrand & Granlund, 2009). The EFI was chosen as it had been suggested as being particularly helpful in understanding the needs of immigrant families of children with ASD (Welterlin & LaRue, 2007). The interview format was used in study 2. To answer the study’s research questions, questions derived and modified from Kleinman’s original set of eight questions (Levy et al. 2003) eliciting responses on causes of ASD and treatment expectations were integrated into the interview protocol. These questions were: What do you think caused autism? What kind of treatment do you think your child should receive? What do you expect from this treatment?

Family demographic profile (FDP)

The Family Demographic Profile (FDP) is a questionnaire with structured questions to elicit socio-demographic information about the child and the family members. The EDP is a modified version of the Parent Interview format used to investigate parental experiences of adults with ASD in the context of India (Daley, Weisner, & Singhal, 2014). The original version consists of 9 sections with structured closed and open-ended questions that capture various aspects of life of an adult with ASD and his/her family. For the purpose of the present study, only the first section of the instrument called “Background Information” was used. The questions in this section were translated into Swedish, and where it was possible, were adapted to specifics of the Swedish context, e.g. for questions regarding family income, Swedish currency, krona. The instrument was used in study 2.

GAP-REACH checklist

The checklist consists of 16 item domains and guiding representative questions for each domain. The domains are grouped around traditional format for original articles: Introduction, Methods, Results, and Discussion. The
reported interrater reliability (IRR) of the checklist is $\kappa = 0.91$, and the internal consistency is $\alpha = 0.885$ (Lewis-Fernández et al., 2013; see Table 5 for description of domains). The checklist was used for data extraction and data analysis in Study 1.

Table 5. GAP-REACH checklist. Adapted from Lewis-Fernández et al. (2013).

<table>
<thead>
<tr>
<th>Item</th>
<th>Overall REC* use</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>At least one REC term used in the title or abstract (YES/NO)</td>
</tr>
<tr>
<td>2.</td>
<td>At least one REC term used in the article text (YES/NO)</td>
</tr>
<tr>
<td>3.</td>
<td>Definition/conceptualization of REC term(s) provided (YES/NO)</td>
</tr>
</tbody>
</table>

*Introduction/Background*

4. Rationale for study question or design discussed in terms of REC factors (YES/NO)

*Methods*

5. REC included in sampling procedure (YES/NO)
6. Sample described in terms of REC characteristics (YES/NO)
7. Methods described for assessing REC characteristics of participants (YES/NO)
8. Language proficiency of participants specified (YES/NO or N/A)
9. Relevance of REC characteristics of interviewers and participants discussed (YES/NO or N/A)
10. Relevance of language characteristics of interviewers and participants discussed (YES/NO or N/A)
11. Language match between participants and instruments is appropriately described (YES/NO or N/A)
12. Measurement equivalence of instruments described for all REC groups in the study (YES/NO or N/A)

*Results*

13. Effect of REC factors on study outcome(s) tested (YES/NO or N/A)
14. REC factors included in data analysis (YES/NO)

*Discussion*

15. REC emphasized in data interpretation (YES/NO)
16. Study limitations discussed in REC terms (YES/NO)

Explanatory model (Supplementary module 1)

The Explanatory Model supplementary module 1 (APA, 2013) is an expansion of the core CFI aiming at evaluate information about person’s own ideas about the causes of the problem; about effects of the problem over time, and about this person’s views on which treatments would be considered as the most efficacious (Hinton, Lewis-Fernández, Kirmayer, & Weiss, 2016). The use of the module can help clinicians and researchers obtain information about several (and sometimes contradictory) explanations of illness/problem reflecting many aspects of person’s life including social, and cultural, and
therefore, eliminates a possibility for “the error of decontextualization” (Hinton et al., 2016, p.65, emphasis as in original). In research, it is recommended that the supplementary module be used to assess profiles of specific patient groups or caregivers by employing qualitative study designs (Hinton & Hinton, 2016). Supplementary Module 1 consists of 14 questions structured around five domains (Table 6). The supplementary module 1 was used for data analysis in Study 2.

Grandparent needs survey

Grandparent Needs Survey is a modified version of the Needs Survey for Grandparents of Children with Disabilities (Dougherty, 2009), which is based on the original instrument, the Family Needs Survey (Bailey & Simeonsson, 1988 and revised in 1990). The instrument is a 40-item scale (0-no; 1-maybe; 2-yes) with items grouped into seven categories: 1) Information; 2) Family and social support; 3) Financial Support; 4) Explaining to others; 5) Child care; 6) Support from professionals; 7) Community services. Initially the instrument was developed for elicitation of responses from parents about their perceived needs when taking care of with their children with disabilities in order to design better interventions. The Swedish translation of the survey was used earlier in a study that investigated the needs of families of children with various types of disabilities (Roll-Pettersson, 1992; Granlund & Roll-Pettersson, 2001; Roll-Pettersson, 2003). The survey can also be used to investigate perceived needs of other family members such as grandparents (Bailey & Simeonsson, 1988).

For the purposes of the present study several modifications to the survey have been made (e.g. word parents were changed into grandparents); adjustments were also made in the available Swedish translation, where some words and phrases were either omitted or changed in accordance with the currently used terminology, e.g. handikapp was omitted, and omsorg eller service were changed into stöd och insatser. Thus, both the modified version of the Needs Survey for Grandparents of Children with Disabilities (Dougherty, 2009) and modifications of the Swedish translation of the Family Needs Survey (Roll-Pettersson, 1992) informed the present study in terms of organization of the items in every category of the instrument.

However, several items were excluded as not applicable to the Swedish context. For instance, items Accessing after-school activities for my grandchild (Community services); How to ensure my grandchild’s safety in the community (Information). Besides, one item was excluded as it was considered as not yet relevant due to young age of children whose grandparents participated in the study, e.g. Accessing help for my grandchild with a disability to learn life skills or find employment (Community services). Other items excluded were: Meeting with legal advisors to learn about life planning for my grandchild’s future care (Community services), and Meeting and
Table 6. Explanatory models Supplementary module 1. Adapted from Lewis-Fenández et al. (2016).

1. Explanatory Model

GUIDE TO INTERVIEWER: This module aims to clarify the individual’s understanding of the problem based on his or her ideas about cause and mechanism (explanatory models) and past experiences of, or knowing someone with, a similar problem (illness prototypes). The individual may identify the problem as a symptom, a specific term, or expression (e.g. “nerves”, ”being on edge”), a situation “e.g. loss of a job), or a relationship (e.g. conflict with others). In the examples below, the individual’s own words should be used to replace “[PROBLEM]”. If there are multiple problems, each relevant problem can be explored. The following questions may be used to elicit the individual’s understanding and experience of that problem or predicament.

INTRODUCTION FOR THE INDIVIDUAL BEING INTERVIEWED: I would like to understand the problems that bring you here so that I can help you more effectively. I will be asking you some questions to learn more about your own ideas about the causes of your problems and they way they affect your daily life.

General understanding of the problem
1. Can you tell me about how you understand your [PROBLEM]?
2. What did you know about your [PROBLEM] before it affected you?

Illness prototypes
3. Have you ever had anything like your [PROBLEM] before? Please tell me about it.
4. Do you know anyone else, or heard of anyone else, with this [PROBLEM]? If so, please describe that person’s [PROBLEM] and how it affected that person. Do you think this will happen to you too?
5. Have you seen on television, heard on the radio, read in a magazine, or found on the internet anything about [PROBLEM]. Please tell me about it.

Causal explanations
6. Can you tell me what you think caused your [PROBLEM]? (PROBE AS NEEDED: Is there more than one cause that may explain it?)
7. Have your ideas about the cause of the [PROBLEM] changed? How? What changed your ideas about the cause?
8. What do people in your family, friends, or others in your community think caused the [PROBLEM]? (PROBE AS NEEDED: Are there ideas about it different from yours? How so?)

Course of illness
10. What usually happens to people who have this [PROBLEM]? In your own case, what do you think is likely to happen?
11. Do you consider your [PROBLEM] to be serious? Why? What is the worst that could happen?
12. How concerned are other people in your family, friends or community about your having this [PROBLEM]? Please tell me about that.

Help seeking and treatment expectations
13. What do you think is the best way to deal with this kind of problem?
14. What do your family, friends or others in your community think is the best way of dealing with this kind of problem?
talking with other grandparents who have a grandchild like mine (Community services), as they partly overlapped with other items in the survey. In the category Community services, the item asking for responses about needs for medical services for the child in general terms (i.e. Locating medical services that meet my grandchild’s needs) was not used. Instead, two items drawn from the original instrument that specifically asked about needs for a dental care and for a medical doctor we used; it was thought that these items would represent needs of a child with ASD more accurately. In the version of the survey used in this study, the last item in the same category reads as follows: Locating a family doctor or a specialist doctor who can understand my grandchild’s needs. The measure was used in study 3.

Strength and difficulties questionnaire (SDQ-Sve)

To measure grandparents’ perception of grandchild’s difficulties and their impact in terms of chronicity, distress, social impairment, and burden for others, the extended version of the Strength and Difficulties Questionnaire (SDQ) will be used. The 25-item Strength and Difficulties Questionnaire (SDQ) was developed by Goodman (1999) for a brief screening of behavioural attributes of the child. In order to examine parent overall distress and social impairment that may illicit information relevant for service use, the impact supplement was added. The impact supplement consists of five questions. For this study the Swedish translation of the SDQ’s impact supplement will be used. For the purposes of the study, slight modifications to the instrument’s wording were made, e.g. the phrase your child had been changed into your grandchild. The instrument was used in study 3.

Procedure

Study 1

Aims and Research Questions

The primary aim of the literature review study was to assess the scope of reporting ethnicity and other cultural factors in research publications by Swedish scholars involved in empirical research in ASD in children and youth by using the checklist GAP-REACH (Lewis-Fernández et al., 2013). The secondary aim of this study was to test the utility of the checklist for assessing ASD research publications within the Swedish context. The study asked the following research questions based on the existing agreement on the key domains for comprehensive reporting of cultural variables (Lewis-Fernández et al., 2013):
(1) How do Sweden-based researchers define or conceptualize cultural factors in their studies?
(2) How do they describe cultural characteristics of the study participants?
(3) Do the researchers provide rationale for inclusion of cultural factors in the studies?

Sampling
The review was based on a comprehensive search of scientific literature published online between the 13th May 2013 (the DSM-5 publication date in the USA) and the 30th November 2015. For the search and selection strategies as well as for reporting and discussing results, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) standards (Moher et al. 2009) were used where applicable (see supplementary material).

Inclusion/Exclusion Criteria for Studies in the Review:
Original empirical research in autism spectrum disorders; conducted in Sweden; participants involved children 0-18 years diagnosed with ASD and/or their family members; published in English.

Studies excluded:
Literature reviews; meta-analyses; editorials; conceptual/theoretical papers; letters to the editors.

Search Process

Library databases used:
Educational Resource Information Center (ERIC); Cumulative Index to Nursing and Allied Health Literature (CINAHL); MEDLINE; Scopus; Sociological Abstracts; Social Services Abstracts.

Search terms used:
“autism spectrum disorders in children” OR “ASD” OR “Asperger’s syndrome” OR “pervasive disorders” AND “Sweden” OR “Swedish”.

Limiters applied:
Geographic location – Sweden; children 0-18 years; English as a publication language.

Reference management system used:
RefWorks
Data Analysis
Guided by representative questions for each item domain of the checklist, each selected article was read through with close attention paid to information in each section and then coded following the coding guidelines. For each item only one answer was selected. Items 1-7 and 14-16 were scored either positively or negatively (i.e. had yes or no answers); items 8-13 had
yes, no, and an additional option not applicable (N/A) (Lewis-Fernández et al. 2013). During the data extraction phase, special attention was paid to determine if the items 3, 4, and 6 were applicable throughout the texts or the tables where the findings were presented. After the coding process, the GAP-REACH total score was calculated for all reviewed articles. This was done by adding the items scored yes and not applicable, dividing the sum by the total number of items (16), and multiplying by 100%. This allowed each reviewed study obtaining the total GAP-REACH score in percentage, which indicated how well cultural factors were addressed in the article (coded as yes) or did not apply to the research methodology (Lewis-Fernández et al., 2013).

Study 2

Aims and Research Questions
The study aimed to explore parents’ explanatory models of their young children’s ASD. The study asked the following research questions:

1. How do parents from culturally, ethnically and linguistically diverse backgrounds recognize onset of symptoms in their children with ASD?
2. What are the parents’ beliefs about the causes and mechanisms underlying their child’s autism?
3. How do parents seek help for their child, and what treatment decisions do they make after their children obtained formal diagnosis of ASD?

Participants

Inclusion Criteria and Recruitment
To participate in the study, the following inclusion criteria were applied: 1) families with culturally, ethnically and linguistically diverse backgrounds, including Swedish would have young children (2-6 year old) with a clinical diagnosis ASD based on either the ICD-10, the DSM-IV or the DSM-5 diagnostic criteria; 2) children from families with immigrant background would be diagnosed with ASD at least one year after they and their families had settled in Sweden to exclude a possibility of posttraumatic stress disorder in young children exposed to emigration related trauma.

Various strategies for recruitment of participants were utilized. At initial stage of recruitment, purposive sampling was used (Patton, 2002). Child Habilitation Centres (CHC) where families and children obtain support and services thought to be primary gatekeepers in two counties in Middle Sweden (county A and B, respectively). In county A, two CHC were contacted; both centres agreed to cooperate. At the first CHC, seven parents were iden-
tified as potential participants. The consent forms and information letters describing aims of the study, procedure and ethical aspects in Swedish, and envelopes with stamps were posted to the CHC’s contact person. If the parents agreed to participate in the study, they were asked to send their written informed consents directly to the researcher. Initially three parents (all mothers) agreed to participate in the study. Later on one mother withdrew from participating in the study. At the second CHC, total 10 packages including information letters, consent forms and envelopes with stamps (5 in Swedish and 5 in Arabic) were placed in the waiting rooms of the CHC for a period of 6 months. One parent responded and agreed to participate in the study (Figure 5a).

Figure 5a. Recruitment of families for Study 2 at County A. Note: CHC denotes Child Habilitation Centre.

In county B, three CHC were identified for cooperation in the study as the most representative in terms of cultural diversity of their populations. Two centers agreed to cooperate. At the first CHC, six parents were identified according to the inclusion criteria. The consent forms together with information letters in Swedish and Arabic were sent to the CHC. None of the contacted parents agreed to participate in the study. At the second CHC, the
Consent forms together with information letters in Swedish, Arabic, and Polish were emailed to the CHC’s contact person, who further sent the information letters to the identified parents (the number was not specified). Only one parent, a mother, contacted the researcher and agreed to participate in the study (Figure 5b).

Given the difficulty with recruitment, a possibility of using network-based sampling or “snowball” sampling (Yoshikawa et al., 2008) was considered. Further recruitment of eligible study participants went through: 1) professional network (preschool teachers and special educators working with children with ASD); 2) parent support organizations (Autism och Aspergers Förbundet; Somaliska Autism Förening), and 3) non-profit organizations working with preschool teachers and young children with ASD (“Speciel-la”). A final sample of seventeen parents from diverse cultural, ethnic and linguistic backgrounds, representing 15 families from two counties in Middle Sweden and one in the western part of Sweden, participated in the study. Written and verbal consents were obtained from all participating parents. (Figures 5a-c).

Figure 5b. Recruitment of families for Study 2 at County B. Note: CHC denotes Child Habilitation Centre.
Data Collection

Two measures were used: the Family Demographic Profile (FDP) and a semi-structured in-depth interview based on the Ecocultural Family Interview (EFI).

Data Analysis

Descriptive statistics (SPSS, 24.0) was used to calculate mean, median and standard deviation for children’s age of ASD symptoms onset and age of diagnosis. Interviews were transcribed verbatim. Data were analysed deductively using a directed approach to qualitative content analysis (Hsieh & Shannon, 2005). This approach is characterized by a structured process. First, existing theory or prior research is used to identify key concepts as initial coding categories; thus, these initial coding categories are predetermined and defined before (and if necessary, during) analysis. The next step is to determine operational definitions for each category based on the theory or prior research findings; at this stage an initial coding framework for data analysis is formed. Next, guided by research questions, portions of texts in interview transcripts are highlighted using the predetermined categories. If any text cannot be coded using the initial coding framework, new codes are assigned (Hsieh & Shannon, 2005).

In this study, data analysis departed from Kleinman’s (1980) theoretical framework of illness explanatory models. Five domains of the Explanatory Model supplementary module to the core CFI (DSM-5, APA 2013) were used as predetermined coding categories (Table 6). Based on the definitions provided to each domain in the Explanatory Model supplementary module, 14 guiding questions (Hinton et al., 2016), and previous research on ex-
plenary models of illness (Groleau et al., 2006), the following operational definitions were used to analyse data in the study:

1. *Parents’ Understanding of the Problem/Autism* – how parents understand their child’s condition to elaborate aspects of their explanatory model;
2. *Autism Prototypes* – parents’ ideas about their child’s ASD based on knowledge of others with the disorder, media attention to ASD, or the parents’ own past experiences with a similar situation; the source(s) about information that shaped their understanding of the disorder;
3. *Causal Explanations* – perceived causes of the child’s ASD to determine how parents understands its source, reasons, and consequences;
4. *Course of Autism* – how parents understand what happens to their children with ASD and what to expect;
5. *Help Seeking and Treatment Expectations* – parents’ ideas on the most appropriate treatment, intervention and services for their child’s condition.

Using the operational definitions for each coding category, all interview transcripts were read through several times. While reading, different colours were used to highlight different coding categories as described by Zakirova Engstrand and Granlund (2009). Analysis was also guided by the interview questions listed in the CFI – Informant version, the Explanatory Models supplementary module (14 orienting interview questions). Some categories required further identification of subcategories. Each identified subcategory was given a relevant coding label. For instance, the first category required a subcategory “Onset of autism symptoms”, an aspect described by Kleinman et al. (1978) and Kleinman (1980). Newly emerging subcategories were given labels, e.g. “Typically developing children prototypes” to denote parents’ inquiries about some core developmental milestones for typically developing children and compare their children suspected for ASD.

To understand the data further, cross-case analysis was conducted to explore patterns of similarities and dissimilarities between the cases (i.e. families). To be able to answer the study’s research questions, a series of descriptive matrices was created to lay out the data to visualize “what’s there” (Miles & Huberman, 1994). Table 3 (see the Study 2’s manuscript) presents the meta-matrix that formed the basis for subsequent analyses. In this time-ordered display matrix, the rows depict a) categories deductively generated from the CFI Explanatory Module 1, and b) subcategories generated inductively as a result of iterative interaction with the data, representing parents’ perspectives or accounts of specific events or activities. The emergence of these subcategories was also guided by the research questions. The columns
present families (“cases”) denoted as F1, F2, …, F15. The development of
the matrix was dynamic: it constantly evolved as new data were entered after
careful examination of each family case. All emergent subcategories applicable for
each family were then put into the matrix. During this early stage of the analysis,
it became also evident that families’ accounts were time-oriented: from the time of
parents’ initial suspicions to their treatment preferences, which led to adding the rows
coincd as Before diagnosis obtained and After diagnosis obtained. During the cross-case analyses new subcategories
were added into the matrix until further coding was no longer possible, i.e. when data saturation was reached. Thus, the category Parents’ understanding of child’s autism yielded 12 subcategories; Autism prototypes – 5 subcategories; Causal explanations – 18 subcategories; Course of autism – 5; Help-seeking and treatment expectations – 34. A decision was made not to expand the category Autism prototypes and limit it to already empirically established and validated subcategories, namely, “family prototypes”, “media prototypes”, “social prototypes” (Groleau et al., 2006).

The next stage of analysis required examining possible relations between
different categories, subcategories and other information, e.g. parents’ socio-
demographic background, reported children’s age when first ASD signs emerged or when children obtained the ASD diagnosis. To facilitate data analyses, the various strategies were used, such as clustering and making comparisons (Miles & Huberman, 1994); visual displays (e.g., descriptive matrices); T-charts, and flow-diagrams. These strategies helped to synthesize data and report the findings.

Study 3

Aims and Research Questions
The study aimed at investigating grandparents’ perceived needs in relation to
having a young grandchild diagnosed with ASD. The study seeks to answer
the following research questions:

(1) What are the needs of grandparents of a young grandchild with ASD
in relation to information, family and social support, financial support,
explaining to others, child care, professional support, and community service?

(2) What are the associations between grandparents’ socio-demographic characteristics and their needs when having a grandchild with ASD?

(3) What are the associations between grandparents’ perceptions of needs and their perceptions of (a) grandchildren’s difficulties and (b) impact these difficulties might have on grandchildren’s everyday life?

It was hypothesized that (i) grandparents would identify their needs at least
in one of the following areas: information, family and social support, finan-

62
cial support, explaining to others, child care, professional support, and community service. It was also hypothesized that (ii) at least one of the grandparents’ characteristics (age, gender, relation to grandchild with ASD, level of education, employment status, geographic proximity to grandchild with ASD, frequency of meeting grandchild, or health condition) would predict grandparents’ perceived needs; and that (iii) grandparents’ perceptions of grandchild’s difficulties and impact of these difficulties on grandchild would predict grandparents’ needs.

Participants

Inclusion criteria and recruitment

One-hundred (n=120) traditional (non-custodial) grandparents whose grandchildren with ASD were enrolled into intervention programs at Autism Center for Small Children at Habilitation & Health in Stockholm participated in the study (Figure 6). Data were collected during four full-day workshops in March, May, October and November 2017. Grandparents were asked to come to the training venue at Autism Center for Small Children in Stockholm 40 minutes before the course started. Brief information was presented in the Habilitation & Health’s course catalogue. As an incentive for participating in the research project, the grandparents were served free breakfast and fruits at the end of the day.

Upon arrival the grandparents were first verbally informed about the aims of the study, and then they received an information letter and a consent form together with the questionnaires in envelopes. All the questionnaires were administered as hard copies (A4-sized paper). The letters to grandparents contained information concerning the aims of the project and a short description of the procedure. The letter also informed the grandparents about their right to withdraw at any time, and that obtained data would be fully confidential and be used only for the research purposes. In the case if the grandparents expressed their willingness to participate in interviews, they were asked to sign the consent form and to provide contact information.

Data Collection

Data were collected at two time points: before the course started and right after the course ended. This was due to the fact that the study was a part of a larger research project, and one of the goals was to evaluate effectiveness of the training seminar which involved using pre- and post- measures, such as ASD Knowledge scale and Satisfaction with the course scale. For the study included into this thesis, the grandparents were asked to fill in two questionnaires: the demographic profile and the Grandparent Needs Survey before the course start, while the Impact supplement to the Strength and Difficulties questionnaire (SDQ-Sve) was administered after the end of the course.
Figure 6. Participant recruitment for Study 3. Note: W1-W4 indicate workshop number held correspondingly in March, May, October and November 2017.

**Data Analysis**
Participants’ socio-demographic data and responses to the Grandparents Needs Survey were analysed using descriptive statistics (SPSS software program, version 24). Two multiple regression models were created to test the second and the third hypotheses. In the first model, eight demographic variables such as (1) age; (2) gender; (3) lineage; (4) level of education; (5) employment status; (6) health condition; (7) geographic proximity to grandchild with ASD, and (8) frequency of meeting grandchild were included as independent variables. In the second model, the included independent variables were items comprising the SDQ Impact supplement scale (perceived difficulties, total impact score, and perceived burden on grandparent or family). In both models, the dependent variable was grandparents’ needs (sum score of all items). An additional analysis using a non-parametric statistical technique – the Kruskal-Wallis test – was performed to explore the impact of the gender variable on perception of burden.
Trustworthiness/Validity/Reliability

Several measures were undertaken in order to address rigour of the studies’ findings. In **Study 1** the following strategies were used to ensure reliability: (1) **interrater agreement** for two raters, and (2) **code-recode**. Interrater agreement refers to the extent of agreement (i.e. consistency of measurement) among data collectors/coders (McHugh, 2012). Two methods for calculating interrater agreement for each item of the GAP-REACH scale were employed: percentage of agreement and Cohen’s kappa statistics. Two researchers (RZE and NK, i.e. coder 1 and 2, respectively) rated seven randomly selected articles (25% of the total number of the reviewed studies) independently of each other. After that both coders met and discussed disagreements until they reached consensus. After discussion, the researcher (RZE) recoded these articles, and then based on the results of agreement, recalculated the total GAP-REACH score for all articles (n=30).

In **Study 2**, dependability (reliability) was addressed by using two strategies: inter-coder and intra-coder reliability/agreement (Krefting, 1991; Miles & Huberman, 1994). Krefting (1991) describes the procedure as follows: “After coding a segment of data, the researcher would wait at least 2 weeks and then return and recode the same data and compare the results” (p. 221). In the study, the researcher coded and recoded the interviews materials from 15 families over the period of 3 years (2016-2019) by both reading the interview transcripts and listening to audio files. Besides, to ensure consistency of coding two researchers (RZE and the academic supervisor LRP) coded three interview transcripts (≈ 20% of the interview material) independently from each other. Before initiating the coding process, both researchers met and discussed the operational definitions of each category and reached consensus on emerging sub-categories based on one interview transcript. After coding, differences in coding were discussed by both coders until agreement about subcategories was achieved. Percent agreement was 0.86.

Using the terminology proposed by Creswell and Miller (2000), validity procedures in Study 2 were done through the lens of the researcher, of the study participants, and of people external to the study, such as readers and reviewers. Credibility (internal validity) in the Study 2 was established by employing several strategies. First, **triangulation of investigators** that refers to the procedure when convergence of themes or categories is sought among different investigators comprising a research team (Creswell & Miller, 2000). For instance, the researcher and one of the academic supervisors (LRP) discussed several inductively emerging sub-categories during the early stage of the data analyses. Besides, the study draft manuscript had been read and discussed on multiple occasions by the research team – i.e. the researcher and the three academic supervisors (LRP, MWA, and TH). The process was helpful in establishing credibility of the results as all team
members used a diversity of research experiences in their approach the study phenomenon (Krefting, 1991).

Second, member checking was used with several study participants. Member checking refers to a validity procedure when the researcher takes “data and interpretations back to the participants in the study so that they can confirm the credibility of the information and narrative account” (Creswell & Miller, 2000, p. 127). Several authors suggested a number of techniques be applied, e.g. sending transcriptions to get comments on their accuracy; meeting in person to ensure that data reflect participants’ experiences accurately or confirm interpretation of data; sending final narratives for verification (Creswell & Miller, 2000; Krefting, 1991; Miles & Huberman, 1994). In the study, the interview transcripts and summary reports were sent to participants for verification. Besides, during the data collection stage the researcher met with two participants to verify accuracy of the participants’ accounts collected earlier. During one meeting, for instance, one parent confirmed that she did not want the researcher to name her country of origin, which was a crucial moment for the researcher in maintaining the anonymity and integrity of study participants. The third strategy used by the researcher was peer examination (or peer debriefing) that refers to involving colleagues who are experts in qualitative methodology and are external to the research project to review and provide feedback on descriptions and analyses of study’s results (Brantlinger et al., 2005; Krefting, 1991). Discussions of possible problems with methodology knowledgeable peers are also described in the literature as debriefing (Kreftin (1991, p. 219). In the study, after presenting the preliminary results at the so-called 50% seminar, the researcher had a peer debriefing with her colleague – a PhD level researcher – who has an extensive experience in using qualitative research methodology, particularly, in conducting interviews as data collection method. The discussions contributed to a deeper understanding of the inductive approach to data analysis by the researcher. The fourth strategy used to increase credibility of the results, was thick, detailed description, defined as “reporting sufficient quotes and field note descriptions to provide evidence for researchers’ interpretations and conclusions” (Brantlinger et al., 2005, p. 201). The researcher provided quotations from the interview transcripts to support the study’s findings and inferences. Fifth, external auditors – professor-level researchers not involved into the research project – assessed the accuracy of inferences drawn from the study results on several occasions (during the so-called 50%- and 90% seminars prior to dissertation defence). Finally, the researcher has prior experience in interviewing culturally diverse families with children with disabilities using the eco-cultural family interview format (Zakirova Engstrand & Granlund, 2009), which could possibly contribute to credibility of the study findings. Indeed, according to Miles and Huberman (1983, as cited in Krefting, 1990), good investigative skills gained through training or experience can be essential for establishing credibility of research findings.
Transferability (i.e. external validity) on the level of generalizability (Firestone, 1993) from sample-to-population is considered to be rather low in the study. However, on the analytic level (i.e. analytic generalization, or generalization to a theory), the study’s findings showed to be congruent with theoretical assumptions of Kleinman’s (1980) explanatory models framework, thus confirming the theory.

In Study 3, reliability was addressed by assessing internal consistency of two scales – Grandparents Needs Survey and Impact Supplement scale-Swe. Internal consistency refers to the degree to which the items of the scale measure the same construct (Henderson, Aydlett, & Bailey, 1993). According to Pallant (2010), Cronbach’s coefficient alpha is the most commonly used statistic. In this study, Cronbach’s alpha coefficient for the Grandparent Needs Survey (the whole scale) was .93. For the subscales Cronbach’s α were: Information .80; Family and Social Support .88; Financial Support .90; Explaining to others .87; Child Care .74; Support from Professionals .79, and Community Services .84. The internal consistency (Cronbach’s α) for the Impact score scale of the Swedish version of the extended SDQ was .85. However, factor analyses for both scales were not performed as the instruments have been validated in previous studies, although the Impact supplement scale has not been previously validated with traditional (non-custodial) grandparents of children with ASD.

Ethical considerations

Studies 2 and 3 were approved by the Regional Ethics Board in Stockholm (2015/843-31/5 and 2017/286-31/5, respectively).

Safety measures to protect participants’ personal integrity

Under the Personal Data Act (1998:204), the following personal data are considered as being sensitive: data that disclose race or ethnic origin, political opinions, religious or philosophical convictions and membership of trade unions. It is also prohibited to process personal data relating to health or sexual life. To protect families as research participants against the violation of their personal integrity during data collection and data analysis, the following measures were undertaken:

1. Communication with parents as research participants were/is done via telephone calls or electronically (by email or text messages) in order to send/receive information categorized as non-sensitive (e.g. when discussing time and places for interviews).
2. When communicating with the parents electronically, sensitive personal data were not discussed; instead, sensitive personal data relevant to purposes of the proposed study were collected during interviews.
3. The interviews with the parents were recorded and transcribed; during transcriptions and analysis the personal identities of the research participants and other persons’ names and other identifiable personal details will be coded using letters and numbers.
4. All sensitive personal data, as well as information that the Swedish Data Inspection Board (2008) states as being on a par with sensitive personal data (e.g. information on social benefits) were encrypted using special software programs.
5. Data analysis files are stored on a password protected and secure computer. The storage of confidential data on the Stockholm University server is considered to be safe, to where the responsible researcher and the doctor-al student have an access to.
Results and Integration of Data

Study 1

Description of cultural variables in reviewed articles
The analysis revealed that the authors of fourteen out of the 30 reviewed articles (46%) provided various definitions and conceptualizations of ethnicity and cultural factors. Ten of all reviewed studies (33.3%) used geographic region of birth as a proxy for ethnicity to describe samples’ cultural characteristics. The majority of these studies employed population-based, longitudinal register designs. Parental country of birth was the most commonly used proxy for ethnicity although the authors used different operational definitions. Only one study (3.3%) used language as a proxy for ethnicity to describe their sample’s cultural characteristics. The analysis of Introduction/Background sections of the reviewed articles showed that seven studies (23.3%) described the rationale of including cultural factors into their research design (Table 7).

Applicability of GAP-REACH in the Swedish context
The analysis of the reviewed articles demonstrated utility of the GAP-REACH checklist to assess the scope of reporting of culture-related factors in ASD publications within the Swedish context. One noteworthy finding was that none of the reviewed studies used the term ‘race’, and therefore it was not coded.

Study 2

Findings from this study suggest that the ways parents perceived and understood their child’s autism and the way they were engaged in help seeking can be explained by looking at time-oriented relationships, i.e. before and after the diagnosis of ASD was obtained. These relationships are highly complex and unique to each family. The main findings are presented below. The readers are referred to a detailed description of the study’s findings in the manuscript.
Table 7. Results of the analysis using the GAP-REACH checklist.

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Definition of Cultural Variables</th>
<th>Rationale for Inclusion of Cultural Variables</th>
<th>Sample described in terms of cultural characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anclair &amp; Hil-tunen (2014)</td>
<td>yes</td>
<td>no</td>
<td>Geographic region of birth</td>
</tr>
<tr>
<td>Butwicka et al. (2015)</td>
<td>yes</td>
<td>no</td>
<td>Parental country of birth categorized as: a) Sweden, b) Nordic countries, c) outside Nordic countries</td>
</tr>
<tr>
<td>Cederlund et al. (2014)</td>
<td>yes</td>
<td>yes</td>
<td>Parental country of birth categorized as: a) both parents born in Sweden; b) one parent born in another European country; c) one parent born in another part of the world; d) both parents born outside Sweden (either European country or other parts of the world).</td>
</tr>
<tr>
<td>De Bildt et al. (2015)</td>
<td>no</td>
<td>yes</td>
<td>No (= not described)</td>
</tr>
<tr>
<td>Domellöf et al. (2014)</td>
<td>no</td>
<td>yes</td>
<td>No (= not described)</td>
</tr>
<tr>
<td>Fernell et al. (2015)</td>
<td>yes</td>
<td>yes</td>
<td>The 1st cohort group: “the Stockholm Somali group”; the 2nd cohort group based in Gothenburg categorized as a) Swedish, b) miscellaneous (non-Scandinavian, South America, East Africa); c) African/Middle East.</td>
</tr>
<tr>
<td>Gardner et al. (2015)</td>
<td>yes</td>
<td>no</td>
<td>Maternal country of birth categorized as a) mother born in Sweden; b) mother born outside Sweden</td>
</tr>
<tr>
<td>Idring et al. (2015)</td>
<td>yes</td>
<td>no</td>
<td>Maternal country of birth categorized as a) mother born in Sweden; b) mother born outside Sweden with low/high Human Development Index (HDI)</td>
</tr>
<tr>
<td>Idring et al. (2014)</td>
<td>yes</td>
<td>yes</td>
<td>Maternal country of birth categorized as a) mother born in Sweden; b) mother born in Europe outside Sweden; c) mother born outside Europe</td>
</tr>
<tr>
<td>Lee et al. (2015)</td>
<td>yes</td>
<td>no</td>
<td>Maternal country of birth categorized as a) mother born in Sweden; b) mother born in Europe outside Sweden; c) mother born outside Europe</td>
</tr>
<tr>
<td>Löfkvist et al. (2014)</td>
<td>yes</td>
<td>yes</td>
<td>Swedish language proficiency</td>
</tr>
<tr>
<td>Lundström et al. (2015b)</td>
<td>yes</td>
<td>no</td>
<td>No (= not described)</td>
</tr>
<tr>
<td>McEvilly, Wicks &amp; Dalman (2015)</td>
<td>yes</td>
<td>no</td>
<td>No (= not described)</td>
</tr>
<tr>
<td>Sellén et al. (2015)</td>
<td>yes</td>
<td>no</td>
<td>Personal or parental history of migration</td>
</tr>
<tr>
<td>Törn et al. (2015)</td>
<td>yes</td>
<td>no</td>
<td>No (= not described)</td>
</tr>
<tr>
<td>Zander, Sturm &amp; Bölte (2015)</td>
<td>yes</td>
<td>yes</td>
<td>Maternal country of origin</td>
</tr>
</tbody>
</table>
Recognition of autism symptoms onset
Parents reported the time of symptoms onset for their children as ranging from 6 months to 36 months old (\(M = 18.81, SD = 9.68\); Median = 18.00), with the majority of parents reporting symptom onset before the child reached the age of 3 years old (n=12). Some parents noticed the first symptoms during the child’s first year of life. Three parents described their children as following a typical developmental trajectory at first, but as losing acquired skills during children’s second or third year of life.

The results suggest that at the initial stage when first suspicions were raised, parents described using a variety of strategies in order to understand their child’s unusual behaviour. One of the frequently mentioned strategies was parents’ observations of behaviour of typically developing children, and comparison with their child’s behaviour. In doing so, some parents cautiously asked other parents about developmental milestones of their typically developing children, for instance: “I asked other parents about how a child of this age [should] behave. What do you think?”; whereas other parents tried to compare their autistic child with child’s siblings who were not on the spectrum.

Another strategy was the use of Internet with Google as being the most often used search engine for seeking information on behavioural symptoms. For instance, as one father with immigrant background revealed: “I started reading a lot about ‘unresponsive kids’, about everything [the child’s name] was doing, and I saw all the symptoms pointing to autism.” Other sources of information were books or TV programmes in parents’ native languages.

Parents also shared their first concerns with their family members, mostly with their spouses and their own parents. However, several mothers told about their husbands’ disagreement with mothers’ opinions, or even negative attitudes to mothers’ suspicions, thus blaming instead the child’s mother. On the other hand, in some families, child’s grandparents could facilitate parent’s recognition of child’s ASD symptoms. For instance, a Swedish mother recalled about her own parents’ help: “He never liked water; he always screamed if his food was mixed [with some other ingredients] – he was totally hysterical... [and then my] mother reminded me how we behaved [when were small]”. A mother with immigrant background noted: “In the beginning, when [the name of the child] didn’t talk, my mother said: ‘you should check his hearing’”.

Preschool teachers were other significant people in child’s nearest environment who facilitated early recognition of signs of autism. For instance, as one mother with immigrant background shared:

One day it was the father who left [the child’s] at the preschool... and there was a preschool teacher, an old [lady], who said to the father: ‘I believe your child has autism. I have worked with children with autism for 20 years’. He came home, opened the door, and he was crying...
After the diagnostic process was over, and children obtained a formal clinical diagnosis of ASD, some parents with immigrant background reported about their unfamiliarity with the concept of autism, i.e. they had never heard about the word “autism” before they came to Sweden. Parents described using various media, such as TV or online websites to learn about and understand this concept. For instance:

It was a London satellite channel where <…> people could call from all over the world … <…> and I heard about this “autism”; … He [the doctor] talked about autism. I wrote down the word “autism” and I tried to google it in [native language]…

Causal explanations
Data analyses revealed that parents’ perceptions of causes of their child’s autism evolved over time – before and after diagnostic assessment for ASD. Figure 7 shows that parents’ causal explanations before initiating diagnostic assessment for ASD included child’s condition (e.g. colic, epilepsy, hearing impairment), possible reaction to parents’ separation/divorce, and child’s reaction to external environmental influences (e.g. exposure to several languages; physical abuse by a peer at the preschool; exposure to measles infection during trip to home country). Over time, after the clinical diagnosis of ASD was obtained, perceptions of causes of ASD changed. Data analyses could group parental causal explanations after completion of diagnostic assessments for ASD into three main clusters, mainly, definite causes, possible causes, and unknown causes. Among definite causes, parents most frequently mentioned genetic or heredity factors. Vaccinations and supernatural/religious were other mentioned definite causes of ASD.

The analyses also revealed that families could simultaneously hold multiple explanations to their child’s autism depending on a) views and interpretations of extended family members; b) information obtained from health care professionals, and/or c) information independently obtained by parents through various media. As one mother noted at two occasions,

We [the family] believe into several things about [the cause]. At the beginning they [the relatives] asked me: ”Did you do anything to your husband’s mother? Anything? Maybe you said something [to mother-in-law]?”. No! But they believe so, they believe so. They say: ”You said something bad to other [people], that’s why your child became like this”.

And later:
Figure 7. Parents’ perceived causal explanations to their children’s condition before and after diagnostic assessments for ASD.

Problem definition before diagnostic assessment

Reaction to parents’ separation or divorce

Child’s condition:
- epileptic seizures
- baby colic
- hearing impairment
- insomnia

Reaction to external environmental influences:
- stem-cells transplantation;
- exposure to several languages;
- physical abuse by a peer at preschool;
- measles infection during trip to mother’s home country

Lack of knowledge on parental skills
Cultural differences in childcare

Causes of ASD after diagnosis obtained

"I don’t know"/"I cannot say for sure"

Unknown

Genetic/Hereditary
Vaccinations
Supernatural/religious
Medication overdose

Definite Causes

Birth complications
Congenital damage (at prenatal stage)
Reaction to gluten
Reaction to genetically modified food
Vitamin D deficiency
Reaction to parents’ separation
Reaction to inadequate educational support (causing ID)
Reaction to physical abuse by peer at preschool
Head trauma ("fell down when was a baby")

Possible causes
I heard that... doctors on YouTube... in Arabic... this doctor said that it happened to several families whose children were vaccinated. I just heard that, I am not sure about anything. In Sweden they say "no" but in other countries they say "yes". And the problem is not in vaccines themselves, the problem is in metals that don’t disappear <...> Vaccines have substances that protect them from [spoil]ing; when the date expires, these substances that protect vaccines get destroyed and they cause problems for children. The doctors abroad say so. And they also say that if we don’t vaccinate children before age of three, they don’t get autism. <...> In my heart I believe in that. This was first. The second, it can happen that we have low [level] of vitamin D as we have much clothes and we are protected from the sun, so this can happen, they say here in Sweden, the doctors, they believe so. They are not sure but they believe so. They believe also that due to this there are many who have autism among us, [name of ethnic group] people.

Another mother who firmly stated that her child’s diagnosis of tuberous sclerosis was responsible for the child’s autism also believed that her child’s condition was caused by high dosage of anti-epileptic medicine prescribed to her child in home country:

He has tuberous sclerosis. It is not just autism... Autism comes from that disease... tuberous sclerosis. <...> It’s a tumour in the brain and in the heart <...> It is doctors who say that come from the disease. It is little bit ADHD and autism <...> It is the tumour that does this... and he [the child] took too much medicine for epilepsy, too much. <...> He was supposed to... He weighed 8 kg but the took medicine for 50 kg.

Help-seeking and treatment expectations
The analyses revealed that regardless of cultural background, all parents’ sought help and information from healthcare professionals in Sweden before diagnostic assessment for ASD began. Besides, one mother with immigrant background told that she also was actively seeking help from medical doctors in her home country to understand their child’s condition before she came to Sweden. Parents’ treatments’ expectations and preferences after the diagnosis of ASD was obtained included several aspects: (1) parents’ firm beliefs about early intervention and timely support; (2) their own mediating role as a “therapist”, and (3) the use of complementary and alternative medicine (CAM) for some families.

An important finding of the study was that expectations of the parents were not met. For instance, the parents mentioned several issues related to provision of services and treatments. Teachers’ lack of knowledge coupled with rejections of applications by municipalities for getting personal assistants, or delayed access to other services for their children made some parents with immigrant background made some parents feel very frustrated with the support system:
This system is hard, impenetrable... When it comes to [people] with disabilities ... everything looks beautiful just on paper. In reality, they [agencies responsible for provision of disability allowances] cut down everything that can be cut down. They are saving money. It's awful!

Two parents with immigrant background and one Swedish parent reported lack of knowledge about ASD among primary healthcare professionals such as family doctors and nurses – the study’s unexpected finding. For instance, one father recollected:

When I went to a doctor who is 60 [years old], a Swedish doctor... and I told him about my being suspicious that my child was autistic, he said: "What?..." I said: “Autism...”. He: "What? What does it mean? What is it?” ... Well, when you sit next to a 60-year old doctor... who is supposed to be experienced but who doesn’t comprehend and doesn’t know what autism is... It’s a big problem! Then there’s a really big problem in the health care. Really bad!

Study 3

Needs of grandparents of a young grandchild with ASD

Figure 8 shows the results of descriptive analyses based on the seven categories in the Grandparents Needs Survey. Grandparents expressed most needs for information (M = 1.80, SD = .33) followed by needs in topics related to child care (M = 1.14, SD = .577), explaining to others (M = 0.70, SD = .64), needs for family and social support (M = 0.49, SD = .45), professionals support (M = 0.45, SD = .47), community services (M = 0.34, SD = .56). The least expressed needs were for financial support (M = 0.28, SD = .47). In the category Information, the results show that the grandparents expressed most needs for learning more about strategies to help their grandchildren develop skills (M = 1.92, SD = .33), followed by needs to obtain more information about how to handle grandchild’s behaviour (M = 1.88, SD = .39), and information about grandchild’s ASD (M = 1.87, SD = .40). In the category Family and Social Support analyses showed that grandparents needed most support in three areas: talking to grandchild’s parents about concerns related to the grandchild with ASD (M = 0.88, SD = .82); helping the family to discuss problems and reach solutions (M = 0.85, SD = .80), and helping to support each other in the family during difficult times (M = 0.84, SD = .80). Within the Financial Support category grandparents reported most needs in one area: getting any special equipment for grandchild’s needs (M =0.48, SD = .71). Grandparents’ needs within the category Explaining to Other showed most expressed needs in finding reading material about families who have a grandchild like theirs (M =1.04, SD = .81). This was followed by a need to
get assistance in explaining the grandchild’s ASD to other children ($M=0.77$, $SD=.83$), and knowing how to respond when friends, neighbours or strangers ask about the grandchild with ASD ($M = 0.76$, $SD = .80$). In the category Childcare the grandparents reported most needs about learning how to provide adaptive play or recreation experiences for their grandchild ($M =1.60$, $SD = .59$). The least expressed need was locating an appropriate childcare facility for their grandchild with ASD (e.g. preschool; $M = 0.41$, $SD = .81$). The results for the category Professional Support show that grandparents expressed most needs in two areas: learning how to communicate with teachers and other professionals regarding their grandchild with ASD ($M =0.65$, $SD = .75$), and accessing family counselling for parents and grandparents ($M = 0.65$, $SD = .78$). The least expressed need was getting help in meeting with a leader of religious faith (e.g. priest, imam or rabbi; $M =0.02$, $SD = .18$). The results for the Community Service Category shows that grandparents needed help in finding a family doctor or a specialized medical doctor for their grandchild with ASD who could understand their grandchild’s needs ($M =0.41$; $SD = .64$).
Relationships between grandparents’ background and perceived needs
The multiple regression analyses showed no significant associations between grandparents’ demographic variables (age, gender, relation to grandchild; education level, employment status; health condition; geographic proximity, and frequency of contacts with grandchild) and grandparents’ perceptions of needs.

Relationships between grandparents’ needs and perceptions of grandchild’s difficulties
No associations were found between grandparents’ perceptions of needs and (a) their perceptions of grandchild’s difficulties, or (b) perceived impact that these difficulties might have on grandchild’s everyday life. The regression analyses revealed that grandparents’ perceptions of needs were predicted by their perceived burden (β = .352, p < .05). Results of the the Kruskal-Wallis test revealed no statistically significant difference in levels of perception of burden of women (Md = 1, n = 65) and men (Md =1, n = 34): χ² (1, n = 99) = 0.011, p = .918.

Data Integration
Data integration in mixed-method designs is the process when the results from both quantitative and qualitative data are contrasted and compared (Creswell, 2014), and then are integrated into “a coherent whole” (Onwuegbuzie & Leech, 2006, p. 491). In the present dissertation, the researcher followed the recommendations provided by Bazeley and Kemp (2012) and Bazeley (2015) for integrating data on the analytic and interpretation level when using mixed-methods designs. First, in order to integrate data across three included studies, a triangulation technique was used to identify overlapping themes in data across all three studies. Bazeley and Kemp (2012) described triangulation metaphorically as “a technique for mapping by surveyors” and as an approach that combines “two different types of knowledge (the lines and angles of the triangle) to point to information beyond what is already known in order to construct new knowledge” (p. 61).

The second strategy utilized to integrate data is the use of theoretical frameworks (Bazeley, 2015). Thus, guided by the aims of the research projects, for data integration and interpretation of the results, the researcher applied two operational models developed for research purposes – the Wachs’s (2000) multiple-influences model and the Process-Person-Context-Time (PPCT) proposed by Bronfenbrenner and Morris (2006). When applied to three studies, the multiple-influences model showed to be useful in identifying both proximal and distal environmental factors, whereas the PPCT model was used to interpret the obtained data. Finally, visual displays as a third strategy for data integration were also used (Bazeley, 2015). A matrix
was designed as a visual presentation of identified proximal and distal environmental influences across studies (Table 8). A visual display of interaction of these influences across various ecological levels using Bronfenbrenner’s (1979) ecological model is presented in Figure 9.

Table 8. Proximal and distal environmental factors identified in the studies.

<table>
<thead>
<tr>
<th>Dimensions</th>
<th>Study 1</th>
<th>Study 2</th>
<th>Study 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Proximal environmental influences</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Belief systems of immediate family (parents and siblings)</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>b) Preschool teachers</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>c) Services providers</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td><strong>Distal environmental influences</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) Beliefs of extended family (grandparents and other)</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>b) Family cultural, ethnic and linguistic background</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>c) Family socio-economic characteristics (occupational background and education level)</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>d) Cultural context of Sweden</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>- national legislation on healthcare, educational and social services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) International laws and regulations</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>f) Information sources</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>g) Conceptualization and clinical definition of ASD</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>
Data Interpretation/Discussion

The primary aim of the present thesis was to identify and describe proximal and distal environmental factors and processes affecting implementation and provision of interventions and services for young children diagnosed with ASD and their families within the context of the Swedish support system. Studies included into the thesis investigated (a) the scope of reporting cultural variables in research publications by ASD Swedish researchers who involved children with ASD and their family members (Study 1); (b) culturally diverse parents’ perceptions of their child’s autism, causal beliefs, and perceptions of treatment options (Study 2), and grandparents’ perceived needs in relation to having a young grandchild with ASD (Study 3). Investigation of the complexity of these aspects required the use of an integrative approach to methods of inquiry – both quantitative and qualitative (van de Vijver et al., 2010). Therefore, the research project was conducted using the convergent parallel mixed methods design (Creswell, 2014). In this section, first the findings of data integration will be briefly presented and then discussed in relation to the aims of the research project using the PPCT model (Bronfenbrenner & Morris, 2006). This will be followed by the discussion of methodological aspects. Lastly, implications for practice will be described.

Proximal and distal environmental factors

Proximal environmental factors have been defined as “specific social, physical, or symbolic contextual characteristics that directly impinge on the child” (Wachs, 2000, p. 125). The results of data triangulation across three studies show that within the Swedish support system, three proximal environmental factors appeared to be as the most prominent in the way they could affect identification of autism in young children and families’ use of services and interventions before and after the child obtained a formal diagnosis of ASD. These are parents’ belief systems (including perceptions about child’s condition, help-seeking behaviours, and treatment preferences); the role of preschool teachers, and the role of other service providers, such as healthcare
professionals (Table 8). Distal environmental factors include influences found in child’s exo- and macrosystems (Bronfenbrenner, 1979) that encompass “cultural and subcultural characteristics, societal institutions, societal disruptions, place of residence, social class, and parental work situation or social support system” (Wachs, 2000, p. 153). Data triangulation singled out seven groups of distal environmental factors that could affect identification of autism and families’ utilisation of ASD-related services (see Figure 8). Three of these factors – conceptualization and clinical definition of ASD (as reflected in DSM and ICD classifications), international laws and regulations, and information sources (including researchers’ networks) could be described as environmental influences of the Trans-national system, which could be considered as an extension of the Bronfenbrenner’s (1979) ecological model. Below follows the discussion of these findings using the Process-Person-Context-Time (PPCT) model proposed by Bronfenbrenner and Morris (2006). However, while interpreting the results, the researcher took the liberty to describe the main components of the model in a slightly different order, i.e. Person-Process-Context-Time.

Person

Child characteristics
According to Bronfenbrenner and Morris (2006), child’s age and gender are among demands characteristics that are important to consider. All three studies included in the present thesis describe children’s age characteristics. For instance, in Study 1, the inclusion criteria were child’s age that ranged from 0 to 18 years, while in Studies 2 and 3, children’s age ranged from 2 to 6 years and 11 months. An important and relevant finding from Study 2 was that the average age when parents first became concerned about their children’s development was 18.81 months, which is consistent with findings reported in the literature (Amaral et al., 2019; Becerra-Culqui, et al., 2018). Child gender as another demand characteristic of the person is reflected in the findings on sex ratio in Studies 2 and 3: in both studies, boy to girl ratio was 3:1. This is consistent with the reported evidence on sex ratio in young children with autism (Rutherford et al., 2016).

In the PPCT model, child’s developmental trajectory can be shaped by his/her behavioral disposition or developmental resources. In relation to atypical development, Bronfenbrenner and Morris (2006) described Person’s ‘developmentally disruptive characteristics’ and Person’s ‘liabilities’ that can affect proximal processes (p. 810). Examples of children’s developmentally disruptive features are child being inattentive, unresponsive, or showing lack of interest in social environment; examples of liability include “conditions that limit or disrupt the functional integrity of the organism” (p. 812),
Figure 9. A schematic presentation of distal and proximal environmental factors influencing the child and the family using Bronfenbrenner’s (1979) ecological model of human development.
such as genetic defects, severe illnesses or disabilities. In fact, as parents in Study 2 reported, child’s lack of interest in objects, lack of eye contact, social withdrawal, disruptive behavior or lack of speech were the reasons why parents sought help from healthcare professionals. Further, in this study several families reported conditions co-existing with ASD consistent with previous research. For instance, one family reported tuberous sclerosis as being one of the definite causes underlying their child’s ASD; two other families revealed that based on genetic test results, specific genetic disorders were identified in their children (although without naming them). Furthermore, the co-existing intellectual disability (ID) in children with autism as reported by parents was 50%, which supports data on the global estimates of IQ levels below 70 in children with ASD (Charman et al., 2011). According to Russel et al. (2019), at present this estimate is regarded as the most reliable for prevalence of ID in children with autism. In addition, several families reported sleep disturbances and behavioural difficulties in their children.

In Study 3, more than half of all grandparents (54.9%) reported that their grandchildren had “definite difficulties” or “severe difficulties” as measured by the Impact supplement scale of the SDQ. However, the results of the descriptive analyses in this study also showed that the overwhelming majority of grandparents (91.1%) did not perceive their grandchildren’s difficulties as a burden either on them or family as a whole, which might not be particularly surprising given the fact that all but one grandparents reported not living together with their grandchildren in the same household. Based on the findings from both studies, one could argue that children’s characteristics described above affected the strength of proximal processes in child’s interactions with family members, especially child’s primary caregivers – parents.

Processes

Complex, shared interactions between the child and child’s significant others occurring regularly and over extended period of time in the child’s nearest settings are called proximal processes – the cornerstone in the bioecological model of human development (Bronfenbrenner & Morris, 2006). In the present research project, the findings from Study 2 are therefore the most informative as they provide insights into the nature of proximal processes from perspectives of the parents of young children with autism. As Proposition II of the bioecological model suggests, proximal processes can differ in its form, content, power and direction depending on the characteristics of the child, environment, child’s developmental outcomes, and observed changes over life span. Based on the results of the study, it would be reasonable to discuss the nature of proximal processes that occurred at two time periods – before the diagnostic assessment for autism was initiated and after the formal diagnosis of ASD was obtained.
Parents reported that it was during their dyadic social interactions with the child they started suspecting a possibility of atypical development—when among the first warning signs listed by parents were child not responding to a name, showing no interest in objects (e.g. birthday presents, Christmas presents), displaying lack of eye contact, or language delay. These initial observations made some parents compare their children’s behaviour with the behaviour of typically developing children—either child’s siblings or peers. Previous research from other countries showed that many parents recognize the early signs of autism within the first two years of children’s lives in such domains as social relationships and language (e.g. Millau et al., 2018; Molteni & Maggiolini, 2014; Shyu, Tsai, & Tsai, 2010). At the same time, the results also suggest that at the mesosystem-level, opinions of children’s other significant people in their environments—grandparents and preschool teachers—could facilitate (or confirm) parents’ recognition of ASD symptoms and then seek help. For instance, in this study three families reported that it was preschool teachers who had raised suspicions about autism. These results indicate that the role of preschool teachers can be paramount in ASD symptom recognition. Based on these accounts, one could argue that teachers could observe children’s behaviour on a daily basis during their active interaction with children or observing patterns of interaction with other children in classrooms. Previous research has showed that preschool teachers could reliably identify early symptoms of autism in young children in preschool settings. For instance, in a Norwegian retrospective study, Larsen, Aasland and Diseth (2018) found no significant differences in ratings of various types of early ASD symptoms between parents and preschool teachers. A study by Westman Andersson (2013) revealed that preschool teachers could rate children suspected for ASD using the ADOS as reliably as clinicians did. Another study (Nilsson Jobs, Bölte & Falck-Ytter, 2019) showed that compared to parents, preschool teachers could rate early ASD symptoms in young children more accurately. However, as the Zhang et al.’s (2019) study revealed, preschool teachers who had advanced training in special needs education and had more work experience could better identify typical and atypical developmental trajectories in young children. These findings suggest that experienced and well qualified preschool teachers as important people in child’s proximal environments can play a significant role in identifying first signs of ASD, and therefore can help parents.

The role of healthcare providers at child health care centers (CHCC)—child nurses, pediatricians and child psychologists—need to be highlighted in the light of the results of the research project. Although qualitative data provided only a glimpse into the interaction between child and healthcare providers based on parents’ perspectives, there is still some evidence (though very limited) that initial diagnostic assessments at child health centers might not always be culturally sensitive. For instance, during the interview with one immigrant mother with cultural background from a Western European
country, whose native language was one of the Germanic languages, told how the child psychologist at the CHCC during her initial psychological assessment of child’s difficulties judged the mother’s way of playing with her child. As this mother recalled, her son was supposed to play with some animal toys together with her, while the psychologist would observe the child’s behavior; however, the mother was not given any instructions on how to play. At the end of the session, the psychologist told the mother that the mother did not play with her son despite the psychologist’s expectations. The mother explained that the way of playing was not typical of her and her child’s culture; she said:

It felt a little bit strange to play in a Swedish way. I don’t play with my children in the Swedish way. I play with them in the [name of ethnicity] way…. So I was just sitting there and I thought that she [the psychologist] would be playing with him…But after the session she told me: You did not play with him.

This is an interesting case because one could see two types of discrepancies in views in relation to child play. First, in spite of the fact that both women (the mother and the psychologist) represent Western cultures, there are cultural differences of views on child play – a finding highlighted in previous studies (Norbury & Sparks, 2013). Second, there is a discrepancy between clinical realities of the parent (the mother) and of the professional (the psychologist), which could be seen in patterns of interactions ‘child-psychologist’, ‘mother-child’ and ‘mother-psychologist that occur in the child’s proximal environment of the CHCC. Kleinman et al. (1978) argued that clinical realities are culturally constructed and vary cross-culturally in various spheres of healthcare, and therefore, these patterns of interactions should be viewed as “transactions between explanatory models” that often involve large discrepancies in values, goals, and expectations (p.254). A consequence of such discrepancies in views is that they could negatively affect clinical assessment, which in turn could lead to inadequate care (Kleinman et al., 1978; Kleinman, 1980). In the field of ASD, research showed that discrepancies in cultural views between parents of children with ASD and healthcare professionals can lead to disparities in diagnostic assessments and access to services (Mandell & Novak, 2005). Future research should investigate interaction patterns in dyads ‘clinician-child’ and ‘clinician-parent’ to explore the ways the clinicians use objects (e.g. toys, dolls) in a culturally sensitive way.

The qualitative data of the project revealed that after diagnostic assessment for ASD and obtaining the formal diagnosis, parent-implemented interventions in naturalistic settings could be described as the most important form of proximal processes driving child’s development. Many parents in Study 2 reported using strategies learned from the habilitation center profes-
sionals with their children at home settings. Many parents, regardless of their cultural background, also reported using their own materials in a creative way and taught their children social, communicative skills on one-to-one mode. These parent-mediated activities were regular and were embedded into their daily routines whether they did toilet training, brushing teeth, dressing/undressing, or reading bedtime stories. In order to do so, parents usually structured their daily activities so that they could devote their time only for their child with autism. Involving parents in interventions to teach social and communicative skills to their children has been described as a successful strategy in the ASD intervention literature (Stahmer, 2015). In Sweden, involving parents in early intervention delivery for young children with ASD is strongly recommended by the heads of habilitations centres (Bohlin et al., 2012).

However, some authors (e.g., McConachie et al., 2014) raised an issue of parents’ adherence to treatment fidelity when providing these interventions at home settings. As McConachie and colleagues noted, “… we do not generally know whether and how often parents actually use the strategies and techniques with their child” (pp. 171-172). Indeed, as the results of Study 2 showed, some parents refused participating in parent education programs provided by habilitation centres, as they believed their child was the best information source in guiding parent-led teaching activities. In addition, one family was skeptic about providing home-based interventions due to parents’ lack of specialized training. The latter finding is in line with previous research with parents of children with ASD in Sweden. Westman Andresson, Miniscalco and Gillberg (2017) found that some parents felt that professionals made parents responsible for implementing various intervention strategies with their children; however, parents perceived that for them it was totally unreasonable to know or to do something they had not been trained for, as compared to professionals trained in special education, psychology or speech-language therapy. These findings are of importance and require researchers’ and practitioners’ attention. Vivanti and Stahmer (2018) argue that professionals’ expectations that parents will implement complex interventions and be responsible for child’s outcomes can be overwhelming for parents. Moreover, as the latest evidence indicates, parent education models for social communication outcomes without active supervision from professionals could be less effective compared to interventions including “active hands-on coaching” (IACC, 2017, p. 47). As Vivanti and Stahmer (2018) noted,

Delegation of intervention responsibilities to parents without adequately resourced expert guidance may be counterproductive not only for the child but also for parents. Interventions for ASD are often difficult to master, even for professionals who chose a clinical or educational career path, as the complex needs of children with ASD require complex technical knowledge (p.771).
Research evidence also suggests that there could be specific components, or ‘active ingredients’ of parent-implemented interventions, associated with positive outcomes for children with ASD, e.g. following the child’s lead and synchronization of parents’ behavior with the child’s attention (IACC, 2017). Future research could explore the effectiveness of parent-implemented interventions within the Swedish context. By employing community-based participatory models, future studies could identify essential components of effective parent-led interventions as well as identify strategies that parents use to facilitate positive family functioning (Stahmer & Pellecchia, 2015; Vivanti & Stahmer, 2018).

Regarding Study 3, the results revealed that the grandparents’ often mentioned need was in the topic area of ‘Child care’; more specifically, grandparents wanted to get more information on how to play with their grandchildren with ASD. Given the evidence from the study that more than 50% grandparents met their grandchild with ASD at least once a week, one could assume that grandparents could also be active mediators in developing child’s social-communicative skills through play. Grandparents’ involvement into lives of their grandchildren with ASD is important, which has been highlighted in previous research (Findler, 2007; Prendeville & Kinsella, 2018). However, this area of research has been largely neglected. Future researchers may want to investigate interaction patterns in grandparent-led play activities with their young grandchild with ASD as a form of proximal processes to further explore how these interactions might affect child’s social communication outcomes. This line of research would be beneficial for provision of individualized approaches to early intervention in ASD based on each family’s strength, needs and priorities (Dunst & Trivette, 2009).

Context

Context, according to the bioecological model, encompasses various distal environmental factors found in exo- and macrosystem, which can affect the strength of proximal processes in child’s development (Bronfenbrenner & Morris, 2006). The interplay of distal and proximal environmental factors influencing the child and the family is schematically represented is Figure 8, based on the Bronfenbrenner’s (1979) ecological model of child’s development, although with focus on family. The three studies, included into this dissertation, were conducted in the cultural context of Sweden – a society characterized by its strong welfare system supporting both children and the elderly (Bask, 2015; Kolk, 2014). Important national legislations in healthcare, educational and social services ensure provision of free access to diagnostic and intervention services, representing formal support to children with ASD and their families (Guralnick, 2019). For instance, parents in
Study 2 reported they sought help from CHCCs to understand their children’ atypical behaviour. Available research demonstrates that parental help seeking for their children’s behavioral problems may be influenced by a country’s healthcare system, and could vary in different cultural contexts depending on type of insurance and access to publically funded professional help. For instance, a study by Zwaanswijk et al. (2003) indicated no associations between parents’ socio-economic status and seeking professional support in such Western European countries as Finland, France and the Netherlands, where healthcare is readily accessible and financial constraints generally do not hinder parents from seeking professional support. In Sweden, the social welfare system guarantees free access to universal child healthcare with routine screening for developmental delays (Idring et al., 2012). Possibly, due to this reason, the study’s findings do not support previously reported results from ASD disparities research conducted in other multicultural contexts such as the USA suggesting that parents having higher level of education and belonging to majority cultures were more likely to detect the first signs of autism earlier and contact healthcare professionals earlier (Angell et al., 2018).

Concerning intervention services, the results of both studies 2 and 3 show that family members of young children with ASD obtained various types of services according to respective legislations. For instance, grandparents (Study 3) had an opportunity to participate in a one-day information course designed for grandparents as part of the comprehensive intervention programs offered to families of young children with ASD (0–6 years old) at child habilitation centers (i.e. child disability services). However, participants in Study 2 reported that their children could not get access to some services even though they were eligible for due to their disability status. For instance, several parents revealed their applications for a need of a personal assistant for the child was declined on several occasions; other parents complained that some support services (e.g. speech therapy) were not as intensive as they expected. These results are in line with previous research conducted with parents of children with ASD in Sweden (see Carlsson, Miniscalco, Kadesjö, & Laakso, 2016; Westman Andersson et al., 2017). Indeed, according to the European Autism Action Conference report (EAAC; 2010), Sweden has a strong disability policy in relation to ASD such as Act Concerning Support and Services for Persons with Certain Functional Impairments (LSS, 1994). Nevertheless, significant difficulties in implementing this law have been highlighted, such as (1) lack of knowledge about autism among professionals in educational system, social welfare system, primary health care, and agencies providing employment services; (2) lack of money; and (3) municipalities not acting in accordance with the law for financial reasons (EAAC, 2010, p. 96). As Björck-Akesson and Granlund (2004) argued, in Sweden early intervention services are based on societal needs: “Societal resources are allocated to children according to
needs, based on decisions made by society. Children have the right to services within the resource frames set by society” (p. 583). However, these distal, macrosystemic influences can have a negative effect on child’s developmental outcomes, especially for families with immigrant background. As Wachs (2000) noted, macrosystems can enhance the operation of proximal family processes by providing resources to the family so it can carry out its goals. Alternatively, by systematically denying availability to resources, macrosystems can act to inhibit the behaviour and development of children in certain groups (p. 170).

Indeed, lack of knowledge among preschool teachers working in inclusive settings as compared to teachers working in specialized settings was highlighted by many parents in Study 2. This finding corroborates with previous research conducted with preschool teachers in Sweden (Zakirova Engstrand & Roll-Pettersson, 2014) and reflects the overall situation in Europe (Autism Spectrum Disorders in Europe (ASDEU; 2018), as well as in other cultural contexts (e.g., Al-Sharbati et al., 2015). The importance of inclusion of children with ASD in educational settings and in society at large has been strongly emphasized by leading researchers in the field (see, e.g., Odom, 2019) as inclusion provides opportunity for young children with autism to interact with typically developing peers to achieve optimal social communication outcomes (Hansen, Blakely, Dolata, Raulston, & Machalicek, 2014).

Wachs (2000) argues that variability in personal experiences in institutions (e.g. schools) can influence developmental outcomes through complex linkages between different components of the developmental niche. In Study 2, parents’ negative experiences with the public formal support system – educational, healthcare or social welfare systems – made some parents develop distrust with the support system and, therefore, motivated them to look for private services and other treatment alternatives. Mandell and Novak (2005) argue that lack of trust in healthcare professionals can lead to parents’ use of complementary and alternative medicine (CAM) instead of conventional treatment approaches. As the results of Study 2 showed, families reported using different types of CAM for their children, ranging from ‘natural products’ (e.g., nutritional supplements and diets) to ‘body-mind’ practices (e.g. massage). One family particularly reported using a wide variety of alternative treatments for their child with ASD, including high dosages of vitamins and one potentially harmful treatment – hyperbaric oxygen therapy. Van der Schee and Groenewegen (2010) suggested that there are several determinants that might influence people’s decisions to use CAM in general, e.g., personal experiences with healthcare system and information sources such as media and social network. In the field of autism research, studies show that the use of CAM can be linked to parental beliefs about environmental causes of autism, especially, the measles mumps-rubella (MMR).
vaccines (Chaidez et al., 2018). Moreover, such beliefs are shown to be influenced by parents’ exposure to information from various sources, e.g., media (Bazzano, Zeldin, Schuster, Barrett, & Lehrer, 2012), social media (Tomeni, Vargo, & El-Toukhy, 2017), and social network at local community (Jama et al., 2018). Indeed, in this research project, the results of Study 2 suggest that parents obtained information on possible causal factors of autism or available treatments from Internet websites, social media or television programs, which is in line with previous research (Campbell et al., 2019; Molteni & Maggiolini, 2014; Tomeni et al., 2017). Besides, as some parents told during interviews, they gained information on autism from lectures by leading researchers in the field, organized by local parental organizations.

As for extended family members, i.e. grandparents, their information needs were addressed through the formal support system. In Study 3, grandparents took part in the informational workshops on autism as part of the intervention package designed for families of young children with ASD and delivered by social and healthcare professionals at disability services. As the results of the Grandparent Needs Survey show, grandparents expressed most needs in the category ‘Information’ with top priorities in getting More information about how to help my grandchild develop skills ($M = 1.92, SD = 0.33$), More information about how to handle my grandchild’s behavior ($M = 1.88, SD = 0.39$), and More information about my grandchild’s ASD ($M = 1.87, SD = 0.40$) (items 3-5, respectively). These findings are consistent with previous studies in the field (Hillman et al., 2017; Prendeville & Kinsella, 2018). Moreover, in the category Explaining to Others, grandparents’ needs priorities were on the item 29 Finding reading material about families who have a grandchild like mine ($M = 1.04, SD = 0.81$). Thus, the results of the present research suggest that sources of information for parents and grandparents, may not always be the same. Moreover, sources of information do not coincide for families and researchers. For researchers, international scientific conferences and academic journals are important forums for exchanging ideas, which in part was demonstrated in Study 1 by researchers’ thorough review of scientific literature on topics under their investigation.

Sweden-based scholars and their research activity in the field of ASD research could be considered within the frames of the exosystem (Bronfenbrenner, 1979), thus, indirectly affecting children with autism and their families as a distal environmental factor. For instance, as the results of Study 1 show, Swedish ASD researchers follow the global trend in autism research (Graff et al., 2014) with most scholarly efforts dedicating to biomedical research (60%), while intervention studies and studies exploring quality of life and family well-being topics covering only 10% in each research area. Moreover, as the results indicate, only a few clinical and/or interventions studies reported involving participants with other cultural backgrounds than Swedish, and using interpreters to communicate with them (see e.g., Zander,
Another characteristic feature of the Swedish society is its rather individualistic, “time-driven” culture (Wachs, 2000, p.167), where two-generation families are more prevalent (Fors & Lennartsson, 2008), as opposed to collectivistic cultures characterized with strong inter-generational support and interdependence (Wachs, 2000). Findings in Studies 2 and 3 support this description to some extent. For instance, the results of Study 2 revealed that all 15 families included only child’s nuclear family members, i.e. parents and siblings, while in Study 3 only one grandparent reported living in the same household as the child’s parent. On the other hand, the results of these studies also suggest that the simplistic dichotomy individualistic vs. collectivistic cannot fully describe the complexity of interrelations on different ecological levels of the family system where child with autism is present. For instance, both studies 2 and 3 revealed that grandparents could be important providers of support to parents and children with ASD. As Wachs (2000) pointed out, social support network that include extended family members can function as both proximal and distal environmental factors thus influencing child developmental outcomes. In this connection, the role of grandparents is unique as the level of support provided by these family members can function as either proximal or distal environmental influence depending on each individual family. As the results of Study 2 show, child’s grandparents in two Swedish families provided regular instrumental support to their grandchildren with ASD and their adult children. Furthermore, the quantitative data (Study 3) show that 61% of grandparents reported living in close proximity to their grandchild with ASD (with one grandparent living together in the same household) with the possibility to meet the grandchild regularly at least once a week. Previous research with Swedish families (although not disability related) demonstrated that geographic proximity of older generation to their grandchildren and adult children was identified as a significant factor influencing provision of social support within families (Kolk, 2017). In the field of ASD research with grandparents, it has been argued that several aspects could affect the amount of support provided by grandparents to their grandchildren with autism, namely, positive relationships with their adult children and solidarity with them on what support should be given to the child, as well as good knowledge about autism (D’Astous, Wright, Wright, & Diener, 2013). Thus, one could assume that the very fact that grandparents participated in the information seminars on autism provided by disability services, could indicate that these grandparents had close relationships with their adult children and were committed to their grandchild with ASD. Unfortunately, regression analyses did not permit
exploring the nature of these relationships. Indeed, as Bronfenbrenner and Morris (2006) noted, multiple regression models can show only linear relationships and therefore cannot fully capture complex, nonlinear relations.

Concerning grandparents of children with immigrant background, the situation seems to be more complex based on the interview results (Study 2). As the findings show, these families, especially those with background in collectivistic view on the family structure, could not always rely on their extended family members, such as grandparents, due to a large geographic distance between them (i.e. they lived abroad at the time of data collection). However, as one parent in the study revealed, her own parents who lived in Sweden could not help her with the child as they were in working age, and had to work to provide themselves. Another factor could be low levels (or absence) of knowledge/awareness of ASD and available support services in Sweden among grandparents.

However, social support network is not limited to extended family members only; it may also include friends as important sources of support contributing to families’ well-being. The results of Study 2 indicate that regardless of their ethnic backgrounds, families reported decrease of social contacts with their friends, which is consistent with previous studies (e.g. Molteni & Maggiolini, 2014). Yet, regarding parents with immigrant background, it seemed that this situation made them feel particularly vulnerable as they appeared not to have additional resources to cope with their difficult life situation – being left without support from their own parents or friends. As one parent bitterly shared,

When I came to Sweden, I tried to help all my friends in any way I could, all the time. But when [the name of the child] appeared, and I needed their help… then I realized something else about the Swedish society – it is very selfish!

Moreover, some immigrant families in Study 2 reported lack of understanding about their child’s autism among their extended family members or members of local community, which contributes to their isolation even more as this can be associated with social stigma attached to mental illnesses that can be prevalent in societies where public awareness about ASD is low (Al Khateeb, Kaczmarek, & Al Hadidid, 2019; Minhas et al., 2015; Wallace et al., 2012). Indeed, one of the findings of Study 2 was that some extended family members with backgrounds from traditional cultures believed that parents’ wrong-doing could cause autism in the child, which is consistent with earlier studies. For instance, in a study conducted in Malaysia (Ilias et al., 2017) it was revealed that lack of knowledge about ASD on the societal level made parents bear responsibility and guilt for their child’s condition – they were blamed for being “bad parents” for their children’s “naughty” behaviour and not being well disciplined (p.80). Other authors (Gona et al.,
also argued that traditional healing systems that are accessible and largely available (as compared to Western-type biomedical healthcare system) tend to blame child’s parents for their child’s disability. Besides, these authors pointed out that in some traditional societies, the prevailing cultural view of individuals with mental illnesses or disability is that these individuals are possessed with evil spirits, ghosts, or have been affected by some other supernatural forces sent by curses or witchcraft (e.g., Gona et al., Ilias et al., 2017; Ouhiti et al., 2015). Cultural beliefs like that resulting from lack of knowledge can lead to inevitable consequences such as stigmatization of children and their families in their communities (Hinton et al., 2016). In Study 2, negative attitudes expressed by some fathers (as reported by child’s mothers) could also be explained by social stigma attached to neurodevelopmental disorders. Previous studies with fathers of children with ASD in other multicultural contexts show somewhat similar findings. For instance, in the USA, fathers of children with ASD from the Mandarin-speaking immigrant families were concerned about social stigma and fear of ‘losing face’ (Wang & West, 2016). In Latino families, fathers’ traditional views on their male role – ‘machismo’ – was challenged when parenting a child with autism (Zuckerman et al., 2014). Bedouin fathers who were raising children with autism in the Middle East reported their concerns related to shame and stigma (Manor-Binyamini, 2018).

The study’s findings discussed above could also suggest that within the Swedish cultural context, there may be a misfit between beliefs about autism held by parents of children diagnosed recently with ASD and beliefs of their extended family members or local community members from similar cultural background, who had never heard about autism before. Wachs (2000) stated with references to previous research: “Although intracultural variability may be stronger for caregiver behavior patterns than for caregiver belief systems, there can be significant intracultural variability when origins of beliefs are contemporary in nature rather than historically rooted” (p. 173). Thus, one can argue that Western conceptualization and definition of autism that parents gradually became familiar with in Sweden due to their child’s condition could contribute to discrepancy in beliefs systems of the parents and of other members of their cultural communities, including extended family members. Professionals should pay attention to these issues when planning family-centered, culturally appropriate interventions.

Despite difficulties that many parents encountered, the interview results, however, showed that parents found the ways to cope with the lack of social support. Here at least two protective factors that should be singled out, namely, the role of parental autism organizations and the role of religion acting as important buffering mechanisms against stress (Wachs, 2000). Participation in activities arranged by parent autism organizations was important for several parents as it provided a forum for exchanging experiences and helpful strategies. As one mother with immigrant background shared:
I feel so happy when I meet with other mothers who are in the same situation as me, because we understand each other, we know what we talk about ... because I don’t get the same type of questions that I usually get from outsiders.

And regardless of their cultural background or religious affiliation, several parents admitted that their faith in God helped them not only to cope with difficult and stressful life situation but also see the meaning of having a child with disability – as a blessing or a gift from God. These findings are supported by previous research (Fox et al., 2017; Gona et al., 2015; Hussein et al., 2018; Jegatheesan, 2011).

One additional finding related to awareness about ASD needs to be especially highlighted. Some parents in Study 2 reported lack of knowledge about autism among primary healthcare professionals, such as family doctors. Although this finding could be viewed as surprising or even unexpected due to the possible assumption that level of public recognition and understanding of autism in the Western societies is higher than in non-Western countries (Hahler & Elsabbagh, 2015; Elsabbagh et al., 2012), this assumption may not be entirely correct. Lack of knowledge of ASD among healthcare practitioners including medical doctors (e.g., pediatricians, family physicians), has been reported previously both in Western and non-Western cultural contexts (e.g., Eseigbe et al., 2015; Ilias et al., 2017; Morris et al. 2019; Wilson & Peterson, 2018), which currently presents a global public health concern in relation to diagnosis and treatment of autism (Wallace et al., 2012).

The findings described and discussed above should be seen in the context of existing international laws and regulations, and other efforts made by the international community. For instance, the most recently revised diagnostic criteria for ASD in the ICD-11 (WHO, 2019) are rather broad in their descriptions, which could facilitate not only its global applicability (Reed et al., 2019), but could hopefully be more applicable in providing diagnostic assessments for ASD in culturally diverse children in the context of Sweden. As such, the latest revision of the ICD for autism needs be viewed within the broader framework of international acknowledgement of autism as a global public health issue and of a strong need for improvement of quality of life and well-being of people with ASD, which is reflected in a number of the UN and the WHO initiatives. For instance, following the adoption of the UN Convention on the Rights of Persons with Disability (CRPD) in 2006 and acknowledging the UN Convention on the Rights of the Child (1989), on December 18, 2007 the UN General Assembly adopted a resolution on World Autism Awareness Day (A/RES/62/139), where the 2nd April was declared to be the day to raise public awareness on ASD globally. The resolution particularly encourages the UN Member States “to take measures to raise awareness throughout society, including at the family level, regarding children with autism” (p.2). Since then, every year in April the UN...
Secretary-General usually sends a message to the global community (UN, n.d.). In 2019, this message was formulated by Secretary-General António Guterres as follows:

On World Autism Awareness Day, we speak out against discrimination, celebrate the diversity of our global community and strengthen our commitment to the full inclusion and participation of people with autism. Supporting them to achieve their full potential is a vital part of our efforts to uphold the core promise of the 2030 Agenda for Sustainable Development: to leave no one behind (UN, 2019).

Similarly, the WHO Assembly (WHA) adopted a resolution on Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders (WHO, WHA 67.8, 2014) to address the concerns that globally, people with ASD and their families are at risk of facing social stigma, isolation and discrimination; and therefore, called the Member States to undertake measures to increase knowledge about autism and ensure access to services for individuals with ASD.

On the level of the European Union, several measures have been undertaken to address challenges that individuals with ASD and their families encounter. First, in 2010, the European Commission adopted the European Disability Strategy 2010-2020 that is built on the CRPD. The Commission identified eight important areas for action: Accessibility, Participation, Equality, Employment, Education and training, Social protection, Health, and External Action (p.4). Within this framework, in 2015 the European Parliament officially adopted the Written Declaration on Autism signed by 418 members of the Parliament. This document calls member states for adopting a shared strategy for autism across European countries to (1) support timely and accurate detection and diagnosis of children and adults with autism; (2) encourage research on ASD and prevalence studies; (3) promote exchange of best evidence-based practices in autism interventions for children with ASD, and (4) support and habilitation services for adults (p. 2). Siniscalco and Gallone (2015) noted that this was the first important step to recognition of autism as a public health priority within the European context. However, as Roleska et al. (2018) argue, “So far, no European Strategy for Autism has been developed” (p. 9).

Time

ASD is a life-long condition and requires continuous support across life-span (IAAC, 2017). The time dimension on the level of individual child is especially vivid in Study 3 when chronicity of ASD in grandchildren was measured by using the SDQ. The results showed that 92% of grandchildren
demonstrated ASD-related symptoms for more than one year. In emphasizing the significance of time Bronfenbrenner and Morris (2006) refer to Elder’s principles of life-span development. The linked lives principle suggests that “lives are lived interdependently and social and historical influences are expressed through this network of shared relationships” (p. 822). Perhaps the most informative example of how this principle works in this research project is its application to the findings of Study 2. One could observe that the study’s results can be explained by looking at time-oriented relationships, i.e. before and after the diagnosis of ASD was obtained, and through the lens of complex interactions between parents, children, professionals, and macro-systemic environmental influences, such as media as described earlier. As the results show, parents’ understanding and perceptions of autism evolved over time in interaction with sources of information about autism, the child’s formal diagnosis, and parents’ active involvement in interventions. This process became especially vivid in cases with some families with immigrant background, when they encountered a new for them word ‘autism’ learned before or during the diagnostic process, and then later when they started using the same word as a tool to describe child’s problems to either extended family members or medical professionals who lacked knowledge about ASD. As Hinton et al. (2016) noted, explanatory models can change over time and can be shaped by contextual influences found in cultural proximal and distal environments.

On a general level, historical changes in conceptualization and clinical definitions of ASD could be viewed within the dimension of macro-time defined as changes in societal expectations within and across generations that can influence (and may be influenced as well) by processes and outcomes over time (Bronfenbrenner & Morris, 2006). The time dimension in the bioecological model is also expressed by such terms as stability and change (p.820). Some findings in Study 1 may indicate changes in autism conceptualizations and definitions over time: the majority of the reviewed articles described their sample characteristics based on ICD or DSM diagnostic criteria that ranged from ICD-7 to ICD-10 versions and from DSM-IV to DSM-5. At the same time, the findings may also indicate some patterns of stability over time in the ways researchers chose to describe cultural characteristics of their samples despite the fact that both DSM-IV and DSM-5 included practical tools for assessing cultural variables during diagnostic process – the OCF (APA, 1994) and the CFI (APA, 2013). However, these findings are rather insufficient in order to draw any firm conclusions in relation to the aim of the present research project.
Scientific Contributions

The findings of the present research project contribute to the scientific literature empirically, methodologically and theoretically. These are summarized below.

Methodological contributions include the use of the novel instruments to address objectives of the studies; e.g., for the first time in the field of ASD research, the GAP-REACH checklist criteria (Lewis-Fernandez et al., 2013) were applied to review scientific literature published by Sweden-based researchers. The application of the GAP-REACH criteria showed to be a promising methodological approach to document reporting of cultural factors in research publications addressing possible culture-related disparities in service provision which could potentially affect culturally and linguistically diverse children with ASD and their families in Sweden. Furthermore, no prior studies in the field has used the CFI’s supplementary module – Explanatory Model (APA, 2013) – as a content-analytic method to examine data collected from parents of young children with ASD in order to investigate parents’ explanatory models of autism. An additional methodological contribution of the present thesis is the usage of mixed methods to facilitate data triangulation across three studies, which allowed obtaining a meta-perspective of a seemingly unrelated, yet closely interconnected array of proximal and distal contextual factors affecting young children with autism and their families.

Insights gained from the studies contribute to the field empirically. The studies are original – the research questions in the studies were investigated for the first time within the cultural context of Sweden, thus, addressing existing gaps in research in relation to families of children with ASD. For instance, unlike previous qualitative studies in the field (e.g. Carlsson et al., 2016), parents who participated in interviews within the frames of the present project were from diverse cultural, ethnic and linguistic backgrounds. The study’s findings also indicate that regardless of parents’ cultural/ethnic background autism in their young children was identified and diagnosed early within the context of the Swedish formal support system. Besides, the study results point to the importance of parent autism organizations as being a protective factor for parents with immigrant background.

Furthermore, grandparenting a young grandchild with ASD had not previously received attention in Sweden, and therefore, it can be argued that findings from the present research project shed light into grandparenthood under these unique circumstances and provide invaluable information for planning and provision of quality family-centred early intervention services based on identified needs of grandparents.

This thesis contributes theoretically to the field of ASD research. Empirical findings of the project suggest a possibility of extending Bronfenbrenner’s bioecological model of child development by introducing an additional
ecological level coined in this thesis as Transnational system to acknowledge the significance of broader contextual influences as part of the globalization process that might affect developmental outcomes of a young child with ASD. Some authors (e.g., Thompson, 2012) suggested using Bronfenbrenner’s ecological model as a conceptual framework to study effects of globalization on child development, although within the existing ecological levels of micro-, meso-, and macrosystem originally proposed by Bronfenbrenner (1979). Nevertheless, evidence generated by the present research project indicate that in studying children with neurodevelopmental disorders such as autism, the influence of at least one aspect of globalization should be given a special consideration – transnational communication systems (e.g., social media, Internet search engines such as Google, or satellite television) – that connect people across national boundaries (Hylland Eriksen, 2014). These communication systems can play an important role in transmitting information to parents of young children on various aspects of ASD. Inaccurate and even false information conveyed through Internet/social media combined with lack of awareness about autism could present a risk factor for child’s development and health due to choices that parents might make, e.g. refusal to vaccinate children due to fear of autism, or choosing ineffective or even harmful treatment alternatives for children diagnosed with ASD. Another example concerns patterns of interactions between transnational external influences with influences and processes found at child’s microsystem – immediate family. For instance, the results of Study 2 suggest that the use of social media by parents with immigrant background allowed them getting prompt informal support from extended family members who lived in other countries. This in turn directly impacted the child with ASD when parents followed advices on treatments given by their own parents or siblings.

In summary, the results of this thesis point to the potential role of multiple proximal and distal environmental influences and processes affecting development of child with ASD in the cultural context of Sweden. Therefore, taking a holistic, systems-oriented approach to assessment and intervention practices for a young child with ASD and his/her families in Sweden is paramount (Björck-Åkesson & Granlund, 2004).

Implications for Practice

Individualization of support and services for children with disabilities and their families is a hallmark in early childhood intervention programmes (Hauser-Cram, Erickson Warfield, Upshur, & Weisner, 2000). Family-systems practices in early ASD intervention should be ideally tailored to family as a unit taking into account its concerns and priorities, supports and resources, and each family members’ strengths, abilities and interests (Dunst
At the same time, these practices should strive to be culturally sensitive (Tincani et al., 2009). The findings of the studies included into the present thesis provide some evidence that could help professionals create individualized interventions for young children diagnosed with ASD and their immediate and extended family members based on their needs, and belief systems. Below are several suggestions that could be considered by professionals involved in ASD early intervention.

For professionals involved into provision of early intervention programmes for children with ASD and their family members:

Sweden is a multicultural society with a larger number of children from immigrant families entering educational and health care services. In order to decrease the risk for health disparities among culturally diverse children with ASD and their families, any planning of any family-centred interventions should be preceded by cultural assessment conducted using available tools, e.g. CFI-Informant version, and its supplementary modules to elicit information on parents’ (and other family members). The eco-cultural family interview format could also be used by special educators both in healthcare and educational settings. This can help elicit parents’ causal beliefs about autism and understand parents’ treatment preferences. By applying items of the GAP-REACH checklist, practitioners can critically assess research findings and pay attention to methods researchers chose to describe cultural characteristics of their study participants.

It is of importance that the CHCC professionals strive to build empathic rapport with culturally diverse parents of young children and gain mothers’ trust, which is crucial in their decisions to vaccinate their children. Lack of trust in healthcare professionals could lead to parents’ choosing not to immunize children for measles due to fear that vaccines might cause autism in their children (see Bazzano et al., 2012; Jama et al., 2018).

Practitioners providing disability services could serve as bridging partners between families of children with ASD and preschool teachers. For instance, based on the results of Study 3, practitioners can inform preschool teachers about grandparents’ expressed need for meeting their grandchild’s teachers and encourage these teachers to view grandparents as potential partners when providing educational interventions in classroom settings.

With the basis on the system theory, assessment practices should be multidimensional and should always take contextual factors into account. When planning interventions, professionals should consider a wide range of protective and risk environmental factors and their co-varying patterns, and then tailor intervention strategies accordingly (Björck-Åkesson & Granlund, 2004; Wachs, 2000). This would facilitate taking a more individualized approach to intervention for each specific child and his or her family.
For educators at higher educational settings (e.g. universities):
To raise awareness about autism among university students – future teachers and special teachers, educational materials should incorporate information about the CFI into existing curricula. Similarly, existing pre-service general and special educational programs should contain informational component in their curricula on the beneficial role of grandparents in supporting the child with ASD, his/her siblings and parents, as well as other family members in a broader family system network.

Methodological Discussion
The findings of the research project must be viewed in the light of methodological limitations of the included studies as well as several challenges encountered during the research process.

Limitations
There are several theoretical and methodological limitations of the studies that should be mentioned. One limitation is that Studies 2 and 3 employed cross-sectional designs which can be viewed as a theoretical limitation in relation to Bronfenbrenner’s concept of time in the PPCT model (Tudge et al., 2009). Studies using the PPCT model need to be longitudinal in order to be able to observe changes over time (Bronfenbrenner & Morris, 2006). For instance, in Study 2, parents’ experiences of ASD symptoms recognition and changes of causal beliefs about ASD across time were investigated retrospectively, thus, constraining measurement of the Time dimension in the way Bronfenbrenner postulated it. Using a prospective, longitudinal design in investigating parents’ explanatory models of autism could have likely provided more accurate information on nature of parents’ causal beliefs before and after diagnostic process. Nevertheless, the study could detect some patterns of differences that occurred in parents’ understanding of child’s ASD over time – before and after diagnostic assessment.

One limitation of Study 3 is that factor analyses were not performed on the Grandparent Needs Survey. However, this instrument is partly based on the Family Needs Survey (Bailey & Simeonsson, 1988) – the well validated instrument both internationally and in Sweden. Moreover, in the field of family intervention research, Henderson and colleagues (1993) questioned the utility of exploring issues related to traditional, psychometric properties validity of family assessment instruments. The researchers recommended considering social validity of the instruments as this is of more importance if one wants to design individualized interventions, i.e., interventions tailored to specific needs of every family member where there is a child with a disability.
Another limitation of Study 3 concerns the use of the Impact supplement of the SDQ – a well validated measure. However, as the instrument was designed to be used primarily with parents, it became evident that it was not entirely suitable for grandparents in the Swedish cultural context. It appeared that grandparents did not have intensive contact with their grandchildren and were less familiar with daily pressures and difficulties. This resulted in a rather large number of missing data for the items eliciting answers on child’s functioning in everyday life. Moreover, the burden item included into the SDQ Impact supplement scale did not demarcate clearly perceptions of burden for individual grandparent from family as a whole. Perhaps, in future research other, more appropriate instruments could be used, e.g., the Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1997) or Caregiver Health-Related Quality of Life (HRQOL; Ware, Kosinski, & Keller, 1996).

Other limitations concerning both Studies 2 and 3 were that the findings might not be generalized straightly to other cultural contexts on a population level due to differences on the macrosystem level. However, given the aim of the research project, or as Bronfenbrenner and Morris (2006) put it, because of the project’s “discovery mode rather than in the mode of verification” (p. 801), where theory has a major role, the issue of external validity of findings at this initial point of scientific inquiry may not be seen yet as critical. According to Bronfenbrenner and Morris (2006), at the early stage of the discovery process that aims at investigating complex, non-linear relationships among various proximal and distal environmental factors and processes, research designs should be rather generative than confirmatory/disconfirming, and when data that emerged at an initial phase, sets the platform for the next phase of the inquiry. Bronfenbrenner and Morris (2006) emphasized the chief characteristic feature of research design when using the bioecological model:

It must provide a structural framework for displaying the emergent research findings (emphasis added, RZE) in a way that reveals more precisely the pattern of interdependencies that are obtained in the data available. Of primary scientific interest are not those aspects of the observed pattern already anticipated in the existing theoretical model, but those features that point to more differentiated and precise theoretical formulations. These can then be evaluated in the light of new evidence, and, if deemed scientifically promising, can be incorporated in the research design for a next step. (p.802).

Bronfenbrenner and Morris (2006) noted that statistical models used for hypothesis testing to studying linear relationships between variables are not particularly suitable for exploring a nonlinear nature of complex interplay of environmental influences and processes affecting child as it can lead to a loss of important information. Indeed, in Study 3 two multiple regression
models were used to explore possible impact of grandparents’ socio-demographic factors on their perceptions of needs. The results were non-significant. Moreover, the application of the Kruskal-Wallis test also showed absence of a relationship between grandparents’ gender and perceptions of needs despite earlier reported evidence of the impact of gender variable on family perceptions of needs (Wang & Michaels, 2009). Therefore, the use of qualitative research designs is suggested to investigate the phenomenon deeper.

**Challenges**

During the research process the researcher (RZE) encountered several challenges that need to be highlighted, predominantly, in relation to Study 2. These include difficulties in recruiting participants; involving translators; difficulties during transcription of the interviews, and facing ethical dilemmas. Informed by previous research (Waheed et al., 2015; Yoshikawa et al., 2008), *difficulties in recruiting participants*, were addressed by using the following strategies undertaken by the researcher’s: (a) using social network, i.e., asking colleagues – educators who were teaching pre-service special teachers at the university level and special educators who worked in clinical settings; (b) meeting with habilitation personnel at multiple sites to present the aims of the study and expected implications for practice; (c) presenting the aims of the study to representatives of local parent autism organizations; (d) adopting a culturally sensitive approach by translating information letters and consent forms from Swedish into languages identified by habilitation personnel – Arabic and Polish. However, the researcher’s effort to involve a professional, certified *translator* to translate written consent forms from Swedish into Arabic revealed that the translated text contained several stylistic errors that could have affected the comprehension of the content. This was revealed when the researcher decided to verify the content of the text by showing it to a native speaker of Arabic – a professional working at the Transcultural Center in Stockholm. As a result, the researcher had to contact the translator again and ask to make necessary changes in the text. Later, the researcher asked an Arabic-speaking parent who participated in the study if the translation was accurate, and the parent confirmed that the information contained both in the letter and the consent form was conveyed correctly and authentically.

Another challenge encountered during the research process was difficulties that occurred during *transcription of the interviews*. For example, when listening to the audio-files of interviews with families with immigrant background, the researcher sometimes had difficulties to understand meaning of certain words in Swedish due to pronunciation peculiarities. Only by listening the interviews’ audio-files multiple times, it became possible to comprehend parents’ meaning of words. On the other hand, the researcher’s not being a native Swedish speaker, presented difficulties to understand some
slang words used by parents – Swedish native speakers. The researcher sought help from one of her colleagues – a PhD-level researcher within the field of family studies and a native speaker of Swedish – who read an excerpt from the interview transcript and explained the meaning of the word.

The researcher faced a number of ethical dilemmas during the research process. Listening to parents’ stories and asking questions to elicit sensitive information impacted the researcher emotionally. Moreover, during the process of building rapport with the study participants, the researcher’s sharing some of her personal accounts created boundary issues in some instances. To address these issues, the researcher tried to remain non-judgmental and explored her own biases (Bowtell et al., 2013); she also sought advice from a PhD-level researcher who conducted anthropological studies, as well as discussed some of these issues with her academic supervisor (LRP).

Future Research

Based on the results of the study, for future studies it is recommended:

1. Researchers collect information on cultural characteristics of their study participants when conducting clinical assessment studies or intervention trials. These characteristics may include (and are not limited to): language and language dialects; religious and spiritual beliefs; tribal affiliation; geographical backgrounds within their home countries. It is believed that these descriptors can become useful tools at researchers’ hands so that they could give a more nuanced description of cultural characteristics of research samples.

2. Researchers are encouraged to use the CFI assessment tools to assess cultural information which can help address cultural validity of their assessments. The GAP-REACH checklist in modified form can be considered a useful tool in documenting cultural characteristics of study participants in research publications. Specific recommendations for further use are:
   (a) Modifications should be made in relation to the Swedish context, for instance, by removing the ‘race’ variable from the checklist.
   (b) The revised checklist may include fewer items than the original; however, items reflecting essential aspects must be included, such as clear definition of ethnicity and cultural variables; rationale for including these in the study; methods for their ascertainment, and their inclusion in data analysis and interpretation (Lewis-Fernández et al., 2013).
   (c) The revised coding scheme should be developed based on consensus of experts representing multidisciplinary research fields when defining concepts of culture and ethnicity; including professionals with diverse
cultural, ethnic and linguistic backgrounds in process would be advantageous.

3. To address challenges associated with diagnostic assessment tools for ASD concerning their cultural validity, it could be beneficial if Swedish researchers could facilitate the development of culturally sensitive assessment instruments for ASD tailored to specific cultural groups in partnership with researchers in other countries within frames of a global public health strategy for ASD (Wallace et al., 2012). Such instruments could be possibly applied not only in Sweden but also in other high-income western European countries with similar population heterogeneity, as well as in non-Western cultural contexts.

4. Researchers are recommended to use longitudinal, cross-cultural research designs to investigate potential inter- and intracultural differences and commonalities in parental explanatory models.

5. To examine possible relations between grandparents’ needs and socio-demographic characteristics in diverse subgroups of grandparents of young children with ASD, including those with diverse ethnic and cultural background and those living in Sweden’s various geographic areas, researchers should involve more heterogeneous and representative samples selected by using random methods.

6. Researchers should employ qualitative research designs to understand how patterns of relationships between grandparents and their adult children might affect grandparents’ level of involvement with grandchild with ASD which in turn could help understand further the unique needs of grandparents.

7. Longitudinal research designs should be used to understand changes in roles of grandmothers and grandfathers over time when grandparenting a grandchild with ASD.
Autismspektrumtillstånd (AST) är en neuropsykiatrisk funktionsnedsättning som karaktäriseras av svårigheter i sociala och kommunikativa färddigter samt begränsade repetitiva mönster i beteenden, intressen och aktiviteter. För att främja positiv utveckling i ömsesidigt samspel och kommunikativa färddigter för förskolebarn med AST, rekommenderas att insatserna som ges är tidiga, intensiva, och evidensbaserade. Forskning har visat att yngre barn ger varierande respons vid användning av dessa insatser med ca 50% av barnen som visar klara framsteg, medan de andra 50% antingen viser långsamt eller väldigt begränsad utveckling. De stora individuella variationerna i lärande och utveckling pekar på ett stort behov av att individualisera insatser utifrån unika förutsättningar som varje enskilt barn och dess familj har. International forskning har visat att för att kunna förklara barnens varierande respons till tidiga, evidensbaserade insatser samt för att kunna utveckla effektiva interventionsstrategier, bör man studera kontextuella faktorer såsom familjers sociala, kulturella och etniska bakgrund samt karaktäristiska hos stödsystem på lokal och nationell nivå.

Det övergripande syftet med avhandlingen var att identifiera och beskriva proximala (närmaste) och distala (avlägsna) miljöfaktorer som kan påverka planering och genomförande av interventioner och insatser för unga barn med AST och deras familjer i Sverige. Projektet tillämpade forskningsdesignen convergent parallel mixed methods där både kvalitativa och kvantitativa data integrerades för att kunna besvara projektets frågeställningar. I avhandlingen genomfördes tre delstudier med utgångspunkt i ett systemteoretiskt perspektiv på barns utveckling. Studie 1 undersökte omfattningen av rapportering av kultur-relaterade demografiska faktorer hos forskningsdeltagare (barn, ungdomar med AST och/eller deras familjer) i vetenskapliga publikationer av svenska autismforskare; Studie 2 undersökte hur familjer med olika etnisk, kulturell och språklig bakgrund såg på sitt barns autism samt hur de förklarade orsakerna bakom barnets funktionsnedsättning. Studie 3 undersökte vilka behov som mor- och farföräldrar hade kring sina barnbarn med autism.

Med hänsyn till syftet med avhandlingen visade resultatet av datatriangulering av de tre studierna att inom svensk kontext var tre proximala miljöfak-
torer och processer mest betydande för barn med AST och deras familjer. De var (1) föräldrarnas värderingar och trossystem (som innefattar föräldrarnas syn på barnets autism; strategier för att söka hjälp och stöd; val av insatser efter diagnostisk utredning); (2) förskollärares roll och (3) hälsovårdspersonalens roll. Datatrianguleringen kunde påvisa sju typer av distala miljöfaktorer: (1) värderingar och trossystem av andra familjemedlemmar; (2) familjernas etnisk-kulturell och språkliga bakgrund; (3) familjernas socioekonomiska bakgrund; (4) det svenska samhällets stödsystem i form av lagar och förordningar; (5) internationella lagar och förordningar gällande människor med funktionsnedsättning; (6) informationskällor (media och sociala media), och (7) konceptualisering och klinisk definiering av autismspektrumtillstånd som beskrivs i DSM och ICD klassifikationssystem. Resultatet betonar även vikten av forskarnas roll som ytterligare en miljöfaktor som kan indirekt påverka genomförande av interventioner för barn med autism och deras föräldrar med diverse kulturell och språklig bakgrund, när det gäller vilken typ forskningsdesign autism forskarna väljer för sina studier samt hur de beskriver sina studiedeltagare i termer av kultur och etnicitet.

Avhandlingen bidrar med empiriska resultat som ger inblick i familjernas trossystem gällande deras syn på bakomliggande orsaker för deras barns autism; vilka behov de har kring unga barn med AST i familjen samt vilka insatser och stöd familjerna föredrar att få för sina barn. Studiernas resultat visar på betydelse av planering och genomförande av familjecentrerat stöd och insatser för barn med AST och deras familjer inom svensk kontext. Praktiska implikationer och implikationer för framtida forskning diskuteras.

**Nyckelord:** unga barn med autism, familjer med olika kulturell, etnisk och språklig bakgrund, systemteoretiskt perspektiv, föräldrars förklaringsmodeller av autism, mor- och farföräldrars behov, kulturformulering, samhällets stödsystem i Sverige.
Acknowledgments

First of all, I would like to thank my family – here in Sweden, and in Kyrgyzstan. Without your support it would not have been possible for me to begin and finish this research project. Indeed, these years have been the most challenging in my life and only your constant support, understanding and love kept me going! Mom, I am especially thankful to you for believing in me, for giving me the most interesting books to read since I was a young child and for subscribing to many newspapers and journals that taught and inspired me in many different ways – from knitting sweaters and learning about differential diagnosis of internal diseases to deciphering intricacies of international politics and enjoying poems written by the great philosopher scholar Abu Ali ibn Sina (Avicenna). Thank you so much for that, Mom!

I would like to thank all participants – both parents and grandparents who decided to take part in the studies – and whose stories, perspectives and helped understand deeper the lives of families where a young child with autism is present. THANK YOU!

Thank you, my academic supervisors – Prof. Lise Roll-Pettersson, Prof. Mara Westling Allodi and Associate Prof. Tatja Hirvikoski – for your expertise, support and very prompt feedback on every single version or draft of my manuscripts! I really appreciate it!

I am very grateful to Prof. Mats Granlund and Prof. Eva Björck who were my first teachers in Sweden during my master’s programme in 2005-2006 and who introduced me to the system theories perspective for the first time and taught me how to design family-centered interventions for young children with disabilities and chronic illnesses. I am especially grateful to Prof. Samuel Odom for his generous support with my research project since its inception; for insightful suggestions that helped improve the manuscript on parents’ explanatory models as my work on the study progressed. I feel I have been very lucky that you were a guest professor at our Department at the time of my doctoral studies. I would also like to extend my sincere gratitude to Prof. Roberto Lewis-Fernández from Columbia University, USA, for his support and providing permission to use the GAP-REACH checklist in this study, and special thanks to Associate Prof. Sofie Bäärnhielm for providing comments to the manuscript regarding the use of Cultural Formulation Interview in Sweden.
I would like to extend my warmest and most sincere thanks to Prof. Mats Granlund, Prof. Simo Vehmas, Prof. Mikael Heinman, Prof. Gunnar Karlsson, and Dr. Heidi Selenius who were the readers at my 50% - and 90% academic seminars, and whose invaluable and inspiring comments helped improve my work immensely. Thank you so much! I would like to thank Dr. Rebecca Popenoe from Karolinska Institutet for her support when I encountered ethical dilemmas at the beginning of the research project. I also thank Dr. Tatjana Von Rosen from Department of Statistics for helping me understand the mystery of Cohen’s kappa.

I would like to extend my sincere gratitude to all who helped me to get in contact with parents of young children with autism: parental organizations *Autism och Asperger Förbundet* and *Somaliska Autism och Asperger Föreningen*, especially to Zahra Hassan; preschool teachers, and professionals at habilitation centers Carina Bessner and Katarina Warming. I especially thank Maggie Dillner and Anna Löfgren from *Speciella*, and my colleagues Bozena Hautaniemi, Rosalba Dallarche, Lena Olsson, and Irene Pierre for help with recruitment of study participants. I thank Susan Sami, a health communication Officer from Transcultural Center in Stockholm, and Joanna Halabi, for their timely and very efficient help with translation of information letters to participants into Swedish and Polish. I also thank my colleague Dr. Wissam Mounzer for his help with translation from Arabic into English. I especially thank Kristina Andersson and Helena Larsson, from the Autism Center for Small Children for their help with the study design and for providing support during data collection. I would like to thank Carina Lundgren for her help with organization of breakfast and refreshments for grandparents who participated in the study! Thanks to Tiina Holmberg Bergman who was the first person I contacted to before initiating the study with grandparents!

I am also very thankful to my dear teachers, mentors and colleagues both in Sweden and the USA – Lillemor Aneér, Brita Ernberg, Dr. Inger Assarsson, Dr. Diana Berthén, Dr. Helen Knutes Nyqvist, Associate Prof. Åsa Murray, Marion Myhrman, and Prof. Katherine Kidd – for their wisdom, support and guidance both in professionals and personal matters. Thank you!!!

My dearest friends – Dr. Nina Klang, Dr. Jenny Wilder, Laurens Blankers, Esther Kissling, Dasha Ivanova, and Zarima Yashurkayeva – thank you very much for all help and support I got from you all during these years! Nina and Esther, I especially thank you for your prompt help with the GAP-REACH study. Laurens, thank you for your guidance on issues related to protection of sensitive data and your advice on the choice of the encryption programme!

Doctoral fellow students and friends – Maria Gladh, Jude Tah, Ulf Jederlund – thank you, guys, for your fantastic support when I needed it most! I especially thank Malin Lönnerblad and Hampus Bejnö for their generous
help with proofreading. Malin Albinsson, Erika Baraldi, Marie Björk, Henny Rosendahl – thank you so much for interesting and inspiring conversations!

Finally, I would like to thank Department of Special Education for funding the research project in its entirety; thanks to Filéenska Foundation for funding data collection for the study with parents, and to Habilitation & Health, Stockholm County Council, for financial and practical support for the study with grandparents.

Västerås, 24 September 2019

Rano Zakirova Engstrand
References:


American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Arlington, VA: APA.


main Criteria (RDoC). *Psychological Science in the Public Interest*, 18(2), 72-145.


es of society’s support. Neuropsychiatric Disease and Treatment, 13, 1783-1796.


